

Participant ID	HW 001 -Lira
Age	■
Date	18th /Nov/2018
Venue	Nurse's room, LRRH
Interviewer	

OK thank you madam for allowing to be part of this interview. Today is 18th November 2018 and we are seated at nurses room at lira hospital and this is participant 001 and now like we said we are conversing and the conversation is going to be about how we take care of individuals with RHD, Factors that has enabled you take care of them and the difficulties you get in taking care of these patients and then let me first know a little about you

Interviewer: How old are you madam?

Respondent: Roughly I could say ■

Interviewer: Now tell me about your qualifications.

Respondent: My qualifications?

Interviewer: Yes.

Respondent: S.4

Interviewer: S.4 and then after that one, what did you train in?

Respondent: I just came straight to be a ■
■

Interviewer: ■ And how long have you been working here in lira regional referral hospital?

Respondent: ■

Interviewer: ■ up to now?

Respondent: Yes

Interviewer: Ok...that is wonderful and then when did you qualify for ■?

Respondent: That one was around ■

Interviewer: That's is when you qualified?

Respondent: Yes

Interviewer: And then looking at the patients you get, are you aware, which ward are you working?

Respondent: Before I was in the [REDACTED]
[REDACTED]
[REDACTED]

Interviewer: Ok....you are in Paed for RHD?

Respondent: It is a general ward.

Interviewer: Do you get RHD patients?

Respondent: Yes

Interviewer: Ok,

Respondent: When we get, ok we call people to do the test, they referred them to lacor or to Kampala.

Interviewer: Ok...do you handle any patient with RHD?

Respondent: Before?

Interviewer: Yes

Respondent: Ok we handle

Interviewer: **Ok**, looking at the demographics of these patient that you see commonly with the which categories of patients do you see, mainly those with RHD?

Respondent: Mainly the old ages

Interviewer: Old ages?

Respondent: Yes, like from 70's and 80's and among the kids/children rarely, some can be at birth, some can reach at even.....but some can come at birth

Interviewer: At birth?

Respondent: Yes

Interviewer: Then on the ward, do you have other illness that you look at apart from RHD?

Respondent: Yes

Interviewer: Which are the common ones that you look at?

Respondent: They are many, like in the ward where I am working, we have those ones which comes with that ...diagnosis with malaria after doing the investigation, acute diarrhoea, hmm, some could come when they have already done local tonsillectomy, ok and other case

Interviewer: Ok...thank you, and then you are going to tell me about your little training on RHD, rheumatic heart disease, have you received any specific training on RHD?

Respondent: No

Interviewer: You are not ehh...during school time

Respondent: No

Interviewer: You didn't? How about when you are in the ward, have you had any specific training in managing RHD?

Respondent: Ok, we only follow what the doctors prescribe then we keep on maintaining the patient

Interviewer: The patient? But you have never had any formal training?

Respondent: No

Interviewer: On RHD?

Respondent: No

Interviewer: Ok...and then how many patients do you see per day?

Respondent: Rarely....laughs

Interviewer: How about per week?

Respondent: Still rarely

Interviewer: How about in about per month, do you get?

Respondent: No

Interviewer: About per year, how many do you get?

Respondent: In a year, it can appear once, at times let me say once

Interviewer: One, one?

Respondent: I rarely see them

Interviewer: You rarely see them eh..., and so like in a year, you see like one?

Respondent: Let me talk like one.

Interviewer: Ok...thank you. And then and those patients, that person you usually see like in a year, usually are they inpatient or outpatient?

Respondent: Inpatients

Interviewer: Inpatients?

Respondent: Yes

Interviewer: Ok...and then, am interested in knowing what you have been taught about, the little you know about RHD? What are the causes of RHD or rheumatic heart disease? What are the causes?

Respondent: The causes..... I can't tell

Interviewer: But what is your guess?

Respondent: My guess..., my guess, I have seen for all ages, it could be like you know old people, maybe they have stress, they are over stressed

Interviewer: And then do you know any association or the link between sore throat and RHD? Have you heard of that link, do you think it is there?

Respondent: The link of associating to getting sore throat?

Interviewer: Tensolite? Getting RHD, have you heard of the link between the two?

Respondent: No

Interviewer: Do you think it is there?

Respondent: Those things are there

Interviewer: Which things are those things? If someone came with sore throat, do you see any link between the possibilities of that person developing RHD at a later stage?

Respondent: No...not so much

Interviewer: Are the two related

Respondent: No, they are not related, according to melaughs....

Interviewer: So how do you think we can prevent RHD, how can we prevent our society from developing RHD?

Respondent: Ok...maybe we need to talk to our community, if we know into details, we teach them that maybe if you see any condition has started, don't start from down because they have their local people, when they have the problem on oesophagus, they go direct to cutting those local things but when we sensitise them, they can come when any condition started,

Interviewer: They come direct to the hospital?

Respondent: Straight to the hospital

Interviewer: So, you said that they start with the local people?

Respondent: Yeah...outside

Interviewer: So it a common practice around the corner?

Respondent: It is the tradition whatever practiced

Interviewer: Wow! Tell me more about that if you have

Respondent: "Anti" when the child is sick and the child is running temperature, they could come and tell you that ah..., that thing maybe you are having the problem with tonsil and that tonsil, we have to cut it, so they start from out there and cut the thing before and sometimes they say...., I don't know how they call it, either worms or some germs in the body, they could come when they have cut, cut the body that they are removing the germs and the rest of the body, so by the time they come when they have septicaemia and with difficulties in breathing.

Interviewer: OK

Respondent: Yes

Interviewer: Ok...and then, how do you know about those things, laughs...., it looks like you have the ideas about the tonsillitis

Respondent: laughs.....

Interviewer; Where do you get the?

Respondent: When they come and ask them, they will explain, they could explain to you all they have done

Interviewer: Ok

Respondent: Yeah...

Interviewer: And what were you taught about in treating RHD?

Respondent: Those ones, we only wait for what the doctor has prescribed and we follow

Interviewer: No one does, so that means that you have never gotten any idea?

Respondent: No,

Interviewer: About how to manage it

Respondent: So we only follow what doctors ordered in the file

Interviewer: Ok, so what do you understand by the long-term prognosis of RHD? What do you understand about the long term prognosis of RHD?

Respondent: That much I don't know but that condition once the patient is having it hard now to handle because the patient could not move for a long distance

Interviewer: Usually these patients with RHD, when do they decide to come for treatment?

Respondent: Mostly, it's the relative now to bring them,

Interviewer: They could not decide?

Respondent: Yes because once you have that condition, everything becomes difficult for you, moving is a problem, talking is a problem, hmm, everything is difficult

Interviewer: So it's the relative to take actions on them

Respondent: Yes

Interviewer: From your experience, at what point do they come to the hospital, is it immediately they see the problem

Respondent; No, it's difficult to understand immediately but now when they come and explain the signs to the doctor, that's when the doctor will send you for further investigations and the diagnosis come

Interviewer Ok...you tell me, you are going to talk to me about your encounter with these patients who have RHD ,can you recall the last person you worked on who had RHD, who had rheumatic heart disease

Respondent: The last patient was a child and that one was from Barr and we tried him but we lost him

Interviewer: You lost that patient?

Respondent: Yes

Interviewer: So how did they present?

Respondent: Ok the way they present, they look weak, generally weak and as far as you try to give what the doctor has ordered, you don't see any proper improvement, that's what I can answer

Interviewer: Ok, on that visit, what did they do for that....., you said it was a child?

Respondent: Yes

Interviewer: what was done for that child?

Respondent: The treatment?

Interviewer: Yes, what did they do when he came?

Respondent: Anti'', you remains there while they are preparing you for the referrals, they maintain you on treatment and they tell you either they will take you out, either to be operated or not.

Interviewer: So what treatment was that baby on?

Respondent: The one I was handling was on ceftriaxone and genta

Interviewer: On genta?

Respondent: Yes Ok. .and when the baby is becoming weak, they put on de-ten

Interviewer: Ok and then so you told me that you get to see one patient.

Respondent; Yes it's rare and one

Interviewer: Are they old or young?

Respondent: Ok I last saw the young one, ok, I started seeing the old and then the last young one but i don't put my mind so much

Interviewer: But looking like 10 years back, on average which patients were you seeing? What was the age?

Respondent, Ok, you see I told you I was in the lab for some time back but from 2011, I was in adyebo and that is mainly surgical ehh and those cases don't appear there, then I was brought here, that is when I started seeing them

Interviewer And so far you have seen them?

Respondent: Those ones were kids and if they discovered they refer you

Interviewer: Ok kids in school or kids out of school?

Respondent: Kids...no, young ones under breast feeding, ages of breast feeding,2 years below there

Interviewer: Do you think our patients are aware about the association between RHD and sore throat, do you think they know any link?

Respondent: That maybe like if a child has sore throat, the problem can also come in where the attenders or the mothers don't know

Interviewer: They don't know?

Respondent: Yes, they don't know

Interviewer: So if they come to you, what symptoms do they present to you, those patients with RHD? What do they complain about when they come?

Respondent: At times they could come when they have already gone somewhere and they have already told them, then they just come with the real diagnosis and maybe you can just

push them to say some symptoms but for them, they say that my patient has problem of the heart conditions but you as you, what symptoms do you see?

Respondent: Ok those symptoms, you just see when a child is having difficulties in breathing and generally weak and could not feed well

Interviewer: And not feeding well?

Respondent: Yes

Interviewer: Ok

Respondent: And not active, he is not active, they didn't become active

Interviewer: They are not active? So what sort of barriers do they commonly state to getting care that they need, why, what stops them from coming to get the care when they get this disease ,the RHD?

Respondent: Ok they have this local belief that maybe somebody has charmed the child, they maybe when they fall into the hands of somebody who knows that this condition you need to come to the hospital, then that is when they could come to the hospital.

Interviewer: Ok...One of them is belief in charms, what other reasons, what else prevents them from coming?

Respondent: Sometimes, there is maybe they don't have transport for coming

Interviewer: So sometimes its transport? So poverty, belief in charms, what else?

Respondent: Sometime when there are couples hmm, the mother can have maybe the idea of coming and the father may not have that idea of bringing the child to the hospital when the heart is divided

Interviewer: So who usually decides on in a home usually around?

Respondent: It's the father

Interviewer: It's the father?

Respondent: Because it's the father to pull the transport

Interviewer: Those are three, which other reasons?

Respondent: I think that is all that I can say

Interviewer: And then for those that you give treatment, why are some not taking it?

Respondent: when you give them treatment?

Interviewer: Yes

Respondent: But for the kids, they take, then the adults, it's the attendants to be keen on doing, if they are not keen, then.....

Interviewer: To be keen on what?

Respondent: On giving drugs, when the drugs is not here, they will tell the attendants to go and buy this and they will say that there is no money and if the drug is there, then it's the attendants to give

Interviewer: To give? So for the drugs for RHD, are they given for free of charge here?

Respondent: Ok., is it's there, they give free of charge because this is a government hospital

Interviewer: But for you from your work assessment, are the drugs always around?

Respondent: That drug is there

Interviewer: It's there?

Respondent: Yes, when they are ordered, they collect immediately

Interviewer: Ok good to hear, and then how are they treated in your own assessment? When they come for treatment, how are they treated by the health workers?

Respondent: You know these people, they need counselling, when it's a child you need to counsel the mother, if it's the adult you talk to them

Interviewer: And do you get time to talk to them?

Respondent: Yes

Interviewer: when you look at your schedules

Respondent: Yes you have to talk to them usually

Interviewer: And when you look at the time they spend at the facility, how is it

Respondent: It's long

Interviewer: It's long? On average, how much time on one patient?

Respondent: That case if they are not referred, it's a long term, and it's a long term stay in the hospital.

Interviewer: And how do they take this time, how do they take it?

Respondent: Ok, at time the condition can worsen and somebody just pass on

Interviewer: Ok... how about for those outpatients, how much time do they usually spend here?

Respondent: The outpatients but mainly they refer them

Interviewer: They refer them?

Respondent: Out patients they push to the wards

Interviewer: To the wards?

Respondent: For the doctors to manage

Interviewer: To manage? So you dint get a patient well?

Respondent: Ok outpatient there I have never worked there but once they discover your problem, they push you in the wards to be attended to at least where the doctor can handle you carefully

Interviewer: And when you tell them, when you give them dates to come back for appointments, from the time you have been on the wards, what is your general opinion about their appointment?

Respondent: **Ok**, they are good at keeping their appointments

Interviewer: They keep them?

Respondent: They keep

Interviewer: Ok, so what do you think encourages them to keep these appointments? Come back next week, come back this month?

Respondent:'' Anti when they come and they get the proper services and they feel that there is some improvement, they keep on coming back, they keep on coming and even they keep on telling their friends from out that, let's go there, we are getting proper services from there, this is how I was referred and this is how I am now, yes, they make a difference

Interviewer: Ok, what are proper services when you say proper services, expand more on that

Respondent: ‘Anti ‘when they come, that day will be a special day for them

Interviewer: They have a special day?

Respondent: Yes

Interviewer: which day is that?

Respondent: This here I don't know but once they come on appointments, doctors will make sure they have seen those patients because they will see them if they are fair and they will be adding them treatment and then they go back and then they keep on to give them another return date like that

Interviewer: For those that don't come back, what do you think hinder them?

Respondent: The what?

Interviewer: Those who don't come back, who don't get appointments?

Respondent: I don't think they can refuse to come back

Interviewer: They cannot?

Respondent: Unless they have changed their mind of going to another hospital

Interviewer: So usually they come back!

Respondent: They come back and if they want to cross to another hospital, eh...they ask for referral reports

Interviewer: Referral reports? So how about you, now when you are doing your work, helping those RHD patients, what are the barriers or the difficulties that you face as you do your work?

Respondent: ok... The difficulties like from my side I don't get any difficulties, if the doctor is there or my colleagues are there, we can discuss and we handle the patients fairly.

Interviewer: So, as you do your work, you have not had any barrier that you wish would be better as you manage these RHD patients

Respondent: Because when the doctor is there and other cadres, we discuss together, things becomes easier

Interviewer: Ok..., are the doctors there, because you said when the doctor is there, are there times when the doctor is not there?

Respondent: They are always there, in case when they have gone maybe for lunch or around evening there because they cannot keep full time on the wards so they leave behind their numbers and then their contacts

Interviewer: Ok and then, let's look at the local health system barriers, those ones within the respective setting within the health Center, what is not working for you in your system, here as you work, here do you see a gap and you need improvements?

Respondent: A gap?

Interviewer: Yes

Respondent: On those patients who are coming?

Interviewer: In your work, as you do your work here, what do you want to be improved in your general hospital so that you can manage the RHD patients better, so that you can manage them better?

Respondent: Ok, maybe they could have their specialists, that is what I can say because this issue of referring means people from here could not handle, they need to be taken to another level where specialists are

Interviewer: Ok do you have any training needs as you via this area of managing RHD patients?

Respondent: I can have that training

Interviewer: what training would suit you?

Respondent: Maybe to know more about the condition and how to manage them, what treatment can we give to them and their stages?

Interviewer: Ok and the stages, ok and then, any other thing in case they gave you a chance, so before you manage the RHD patient, what are the things you need to know to do?

Respondent: Since I have not yet known more about it, I cannot even know things to have on the ground...laughs....maybe after that study, I will now say ohh...! They need this and that

Interviewer: Ok and then if you look at the leadership, the administration here and the district as a whole, what are some of the gaps

Respondent: The gaps?

Interviewer: What do you think can be done better?

Respondent: I think because here we don't have that unit of intensive care, maybe they can open, but they could not open without the specialist

Interviewer: And then, how is the administration? How are they managing you the health workers, what are the problems you face as you do things here?

Respondent: Here we are fair because we have the area managers, if there is any hardship, you contact them but here I rarely get those challenges

Interviewer: You don't get the challenges?

Respondent: Yes

Interviewer: And then when you look at the funding for health care in general, how is it?

Respondent: The funding? , what? According to the salary or what?

Interviewer: One, ok...let's begin from that, are you comfortable the way you are being paid, ok basing on the work you are doing?

Respondent: ''Anti''salary is there, but small, small motivations

Interviewer: What would motivate you to work better?

Respondent: Ok you know here, there are some people who go for the workshops but not all people

Interviewer: So they select some few?

Respondent: Like me since I came in Paed, I have never gone for the workshop but during that time when I was in the Lab, I could go for the workshop and I was well equipped with the knowledge

Interviewer: Ok,I understand, then if you look at the funding for RHD in particular, are there any barriers, are there things that needs to be brought?

Respondent: That much have not been in the ground, specifically, now, I could not tell

Interviewer: You can't tell?

Respondent...laughs....

Interviewer: And then if you look at the number of health workers who are working on RHD patients, how are the numbers?

Respondent: You see here, like when the patient fall in our wards, ok we work as a team, yeah... So I don't see any difficulties unless if the units were separate, that's when I could say that the staffs are few, but since we work as a team, I don't see any challenge

Interviewer: So do you have any health workers who has been trained on managing RHD patients?

Respondent: From here?

Interviewer: Yes

Respondent: That much I don't know

Interviewer: You don't know? So you don't know anyone who has been trained?

Respondent: No

Interviewer: Ok and then do you think it's important?

Respondent: Yes, it's important

Interviewer: It's important? How do you think it is important to train some **health workers** in management of RHD?

Respondent: At least if somebody trained is there, when the patient comes, you just call him to handle that person because he will handle better than somebody who is not trained

Interviewer: and if you look at the number of patient that you see in a day. How are the numbers?

Respondent: Like from my unit, we could range from 30 to 30 something

Interviewer: 30 something?

Respondent: Yes

Interviewer: How many each day can health workers handle?

Respondent: Ok...we have on shifts

Interviewer: Ok you have shifts?

Respondent: Like day, evening, and night, like day they could be 2-3 people, then evening you work alone and if staffs are many, they could put like 2 of you then night at least one person

Interviewer: One person?

Respondent: Yes

Interviewer: Then how do you find the work load now like on night, one person works?

Respondent: Work like on night when you are alone without student, you can really work until morning without resting

Interviewer: How about during the day?

Respondent: They but at least 2-3 staffs plus students but at night always you are alone

Interviewer: Alone?

Respondent: Evening time also they can put students but with different cadre, it can be like those in second years, you can have diploma nurses and sometimes even degree people can be there, maybe at night the work load can be, at night there are no students but during day and evening, it is fair

Interviewer: Are there at times when you can fail to cover the whole ward?

Respondent: When you are alone?

Interviewer: Yes

Respondent: Then you run day, evening and night, maybe at that shift patients are not there

Interviewer: Now when you are there, you cover?

Respondent: You cover

Interviewer: You must cover?

Respondent: Yes

Interviewer: And then let's look at the medications, especially like the heart failure drugs, the anticoagulation drugs, the BPG drugs and the diagnostic eh... Like for echo-cardiography, is that done here, do they do echo here

Respondent: Yes, they do

Interviewer: What do you have to say about the medication and the distribution of these drugs?

Respondent: You see, if you have that case in your wards, that's when you can have those medications but if you don't have them since they get drugs per file, there is no way you can bring in those drugs at store

Interviewer: Ok now you said that at least per year you get a patient

Respondent: Yes

Interviewer: Of RHD patients, are the drugs there of the RHD

Respondent: If the doctor orders, you go to the pharmacy and collect

Interviewer: And when you go there, do you find the drugs there

Respondent: Yes

Interviewer: And then for the echo, is it available for these patients?

Respondent: "Anti" we call them

Interviewer: You call them?

Respondent: If we see or if the doctor is suspecting a case, they send for them and they go and do them

Interviewer: You do it here or you...

Respondent: Yes

Interviewer: You do here and the services?

Respondent: Yes

Interviewer: Ok and then when you look at the health information and the medical record system, inpatient that register from RHD patients, how is it, what do you have to say about the health system?

Respondent: The medical records?

Interviewer; Yes, how do you manage the information about these RHD patients

Respondent: Because after the discharge, they take back to the boards, I think they're doing well

Interviewer: Ok, so if the patient came back after one year and they needed to retrieve their records, do you get it?

Respondent: Yes, they go for the same file

Interviewer: Is it easy to get that file?

Respondent: yes

Interviewer: So you feel that the records are kept

Respondent: Yes, it's well-kept because they give them the discharge forms, in that discharge form, it will be carrying their numbers from the file, so when they came back, you present your numbers and they give you the file immediately

Interviewer: Ok... on your wards, do you have any guidelines or protocols' for RHD patients? Do you have posters..... do you have guidelines on how to manage RHD patients?

Respondent: Maybe it is there, I have not gone there, we have charts anyway on our wall

Interviewer: Is there any chart which is talking about RHD?

Respondent: I think it's there

Interviewer: You have seen it?

Respondent: Maybe, I have not taken my time to read it but we have a lot

Interviewer: You have a lot on the wall. But you personally, you have not read any chart?

Respondent: I have not picked any interest on

Interviewer: Ok... Have you had any chance to look at the guidelines for management of RHD patients?

Respondent: No

Interviewer: No and then, do you think they are important?

Respondent: They are.....

Interviewer: How important?

Respondent: ‘‘Anti’’ supposed it comes at night, you are alone and your colleagues are not there, so if you have that knowledge, you just apply it to the patient

Interviewer: Ok...do then as a health worker, what is working, which is that thing that is working for you and why do you think it is working for you, what is making your work tick

Respondent: The thing which is making me active?

Interviewer: which is working for you, let me say, what is that advantage you are seeing in this system, in your health system that is working for you or that is making you do your work well

Respondent: In the first place

Interviewer: Yes

Respondent: Before you come, you pick some interest that I want to become a health worker ,secondly ,we are here for life saving then thirdly it’s that work which is also helping us to even pay our children school, now if they suck you out, how will you manage your family

Interviewer: What do you like about this region of the hospital?

Respondent: Here?

Interviewer; Yes

Respondent: I like this place in so many ways, in the first place if you are sick, you are already, the doctors are there for you and your family, then secondly, salary, they pay us in time, we have love, they love us also, they can appreciate us ah...you are hardworking and you feel so happy, laughs....that is what I can say

Interviewer: Who are those people who appreciate you at least?

Respondent: Especially the....., our authority, if you go down there to them, they are like how are you and they introduce you in a very big way...laughs

Interviewer: They can give you names

Respondent: Yes, like for me when I come and they find certain veins, they call me like professor, consultant and the what.....laughs

Interviewer: Consultant comes in and.....

Respondent: ...laughs...

Interviewer: Ok...and what has made you work this here?

Respondent: I work easily, ok, in the first place, they have accommodated me here

Interviewer: As you treat these patients, what has made it easy for you to treat them?

Respondent: Ok, we have things like ok what we need in place is there

Interviewer: Like what?

Respondent: Like the gloves, the syringes, the leads

Interviewer: All those things are there?

Respondent: Yes

Interviewer: And then let me see, so for you, you get your money, the leadership at least they appreciate you and then you have enough health workers, that is what you said here except t night, you always have to work alone

Respondent: yes

Interviewer: But they add on you the students?

Respondent: Yes

Interviewer: Ok, night is always alone?

Respondent: Yes

Interviewer: So the missing link is that you didn't have the guideline for RHD management or you have not just looked at them?

Respondent: I have not checked on all those charts, but I think it is up there

Interviewer: And then you get your salary on time, those are the things that is working for you, the administration is ok, you have the things that you need to do your work like the

gloves and then you said the way your files are kept, you can easily get it, it's ok, so and then generally do you think that your patients like the RHD patients, because it's like now, it is where we have an interest, do they get the care they need here?

Respondent: The care that they need?

Interviewer: Yes

Respondent: They get

Interviewer: They get?

Respondent: Yes

Interviewer: How about for surgery like for those RHD patients who need surgery, do they get here?

Respondent: Sometimes they send them outside the country, that is what I always hear and they tell them to raise some good money to manage

Interviewer: So basically, surgeries are not done here?

Respondent: No, I have never seen it

Interviewer: Ok and then you have told me that many of them are referred

Respondent: Yes

Interviewer: Who are referred? Which RHD patients are referred?

Respondent: Ok... like when you have it, they just tell you we could not manage here especially children, they refer them

Interviewer: They refer them to? Usually, where do they refer them to?

Respondent: They refer them mainly to Mulago

Interviewer: To Mulago and then when they refer them to Mulago, in your view, do you think they continue to Mulago?

Respondent: Yes because at times they could say there are some other machines which are not here to go for those further serious illness issues that is why they always refer them

Interviewer: like which machines are lacking here?

Respondent: I don't know their names

Interviewer: You don't know their names? Laughs...and then do you have any concerns regarding patients safety and the quality of care that is given to your patients, any concerns where you feel the government needs to improve there, the way you handle patients?

Respondent: But from there, I always see, once they have that condition, they really take proper care of you **and** every time somebody has worked on and is leaving, he could report down, you have to write down, day person can report, evening person reports, night reports, they keep on courage

Interviewer: Ok

Respondent: Yes

Interviewer: Looking at your motives and other people you work with, how do you feel when they are handling patients?

Respondent: I think they are handling them well

Interviewer: They are handling them well?

Respondent: Yes

Interviewer: Ok, good to hear that, how about.....have you ever witnessed any death that occurred here that could have been prevented, have the patient been cared for well?

Respondent: I have not

Interviewer: You have not seen any case that you felt like that maybe this case surely was neglected or was not managed well?

Respondent...laughs..., I have not seen

Interviewer: You have not seen that?

Respondent: Yes

Interviewer: Ok, and do you think that there are some RHD patients that are dying from the villages when they have not come for care here?

Respondent: Ok... I don't think they can just die when they have not been taken to any hospital, so they could go and then, time for review come, hmm, maybe poverty can leave them there alone to suffer

Interviewer: So there are some who don't come because

Respondent: Yes, they don't have money

Interviewer: Ok, what else? What else would stop them from coming?

Respondent: I think that is all

Interviewer: Its money?

Respondent: Yes

Interviewer: Ok

Respondent: Because they always try, they try even to beg people

Interviewer: Ok and then in your opinions, what are the two most important things ministry of health should do to ...to improve on the outcome

Respondent: Laughs

Interviewer: Of RHD patients?

Respondent: They should open the unit

Interviewer: units?

Respondent: And let those doctors who are really concerned to be available, so that this means of transport to long distance, going out of the country may not be there because they could not afford like in our country

Interviewer: Anything else that you want to share concerning RHD care that I have not mentioned but you feel that it's important

Respondent: The ones....ok...what I feel, you know those people outside there, ok...their mind is in their family and doing other things but in their health, they wait until when they are really down and they start maybe from the health centers, then health centres start referring them like that and that. So if there was any way health worker who can go out there and talk to them at least

Interviewer: Thank you very, very much for this information that you have shared with us, surely we shall put these things together, what you have told us and what other health workers are going to tell us to come up with the strategies of improving RHD management and prevention, thank you.

Participant ID	HW 002 - Lira
Age	█
Date	18 th Nov/2018
Venue	Nurse's room,LRRH
Interviewer	

Today is the 18th Nov 2018 and we are seated at the nurses' office room at LRRH. You are a pharmacist?

Respondent: Yes,

Interviewer: Ok I just request you to be loud so that I can hear this when am transcribing then remember there is no right or wrong answers and your opinions are very important and we shall keep it confidential, so we need you to be frank or honest as much as you can, ok so let me just know a little bit about you

Interviewer: How old are you?

Respondent: █

Interviewer: What are your qualifications?

Respondent: I am an intern pharmacist █

Interviewer: You graduated █?

Respondent: █

Interviewer: Wow! Ok and...

Respondent: Bachelor of pharmacy

Interviewer: Ok so you came here █

Respondent: Yes, █

Interviewer: █ You have been here for?

Respondent: Making █

Interviewer: █? Ok and then, have you seen any RHD patient coming for maybe medication?

Respondent: The ones I have seen have been looking for medication, now that we don't have a tent, they usually come to the pharmacy, and we are usually on exchange because in the pharmacy, we don't have the drugs, and they have been reluctant but we have the laxatives like Laxis at maximum stock

Interviewer: So you said they have been coming?

Respondent: Yes

Interviewer: That is wonderful, ok then looking at the demographics for the patients that have been coming for treatment, which age group do they fall into? How do you describe them?

Respondent: I would say....

Interviewer: Are they young, are they old. Are they women.....

Respondent: laughs, most of them ok from the observation, I have not been very observant but from my observation, most of them are ladies, yes and the few are the young kids

Interviewer; Kids?

Respondent: Basically there are many who are present

Interviewer: From your observation, are they in school?

Respondent: No, if they are in school, they didn't go to the advanced level so far

Interviewer: Ok

Respondent: Probably past P.7

Interviewer: P.7?

Respondent: Not S.4

Interviewer: Not S.4? and then apart from RHD, which other common illnesses are you treating in the pharmacy?

Respondent: we always receive basing on what is in the hospital, so we treat the patients

Interviewer: And what is most common?

Respondent: What is most common I would say infections because we give out a lot of anti biotics but common among those is peptic ulcers, respiratory infection disease and then sexuality transmitted infection, then some rare cases like T.B infections.

Interviewer: Ok then, how often in a week, how many times do you get prescription for RHD?

Respondent: In a week? Hmm like twice

Interviewer: Twice ehh:

Respondent: Yes

Interviewer: So let's say like 2 per week?

Respondent: Yes 2 per week

Interviewer: Ok then So is it mainly the adults who you treat for infections that you get or it's the pedetriatic/children?

Respondent: Pardon?

Interviewer: Looking at the demographics, do you treat more children than the adults or more adults than the children?

Respondent: Overall on the desk, we treat more adults than the children because the ped ward is opposite almost half empty most of the time

Interviewer: What explains that? What do you think explains that?

Respondent: I don't know exactly maybe it's the facility or they lack residence because even in the emergency ward, you will and mostly see adults and I have never seen the kids there yeah and that is the matter

Interviewer: That is strange, I thought if you would ask me, I would think it is maybe according to the sick...

Respondent: Yes that would be the case but the statistics say otherwise because I haven't gone there

Interviewer; Ok tell me about your training on RHD, have you ever had any training on RHD management?

Respondent: No

Interviewer: No?

Respondent: Honestly, I have not

Interviewer; Ok, maybe in school, did they ever tell you anything about management of RHD?

Respondent: Well in one of those classes when they were talking about clinical pharmacology, they talked about it

Interviewer; They did?

Respondent: Yes

Interviewer: Also you have some clue at least about it, about RHD?

Respondent: Not that the clue

Interviewer: It's a clue eh..?

Respondent: It's not just the clue, the clue will really be in details

Interviewer: Ok and then after the graduation, since graduating, have you ever had any formal training or workshops you have attended where they are talking about RHD?

Respondent: No I have not heard because before I came here I was working at the facility not a clinic, so we usually had CMEs but RHD has never been discussed

Interviewer: Has never appeared? Ok do you think it's necessary to have one? Or do you find it necessary?

Respondent: Yes it's because when you are working at the pharmacy, the patients come, at least you should have an idea about every disease because the patient will come and will say I have this, you have to know how to distinguish, is it RHD, is it a cardio myopathy, is it hypertension, and is it cardiac malfunction, so you have to know about a little bit of everything so that you can know which drugs to give and distinguish because they differs

Interviewer: Ok so currently what are you following? You just follow what the doctor have prescribed?

Respondent: Currently I give based on the duration of the drugs, I always have to consult, why you are giving this one which is longer than it should have been

Interviewer: Ok so do you mainly see the inpatients or the outpatients that mostly come?

Respondent: RHD patients are mostly outpatients

Interviewer: They are outpatient?

Respondent: Yes

Interviewer: Ok and then so according to you, what is RHD? What do you know about it, what is that you know about the disease

Respondent: Not so much

Interviewer: Hmm

Respondent: I know that it involves the heart and the heart controls the body system to pump blood and that blood should come out

Interviewer: And then what could be causing it?

Respondent: Not so much, not so much actually

Interviewer: Are you aware of the link between sore throat and getting RHD, have you ever heard about it?

Respondent: Not really but you can tell me now...laughs

Interviewer: I cannot tell you because I need to know what you know and why we are asking you is because we want to see the gap so that people can be given

Respondent: Ok

Interviewer: The necessary training

Respondent: Ok

Interviewer: Could you be knowing how it can be prevented or how we can prevent RHD

Respondent: Me personally before I am a professional, **like** taking the real life styles, drink a lot of water, enough exercise, eat well or eat right ,if you do all those, you will get a lot of nutrients, so they should eat right laugh...take enough exercise, that is in good condition, that is specifically for RHD patients

Interviewer: You have mentioned some of the treatment you give for the RHD patients, what are the treatment options you know for treating RHD?

Respondent: Most of the time, the prescriptions I have seen, have come with drugs which also treat hypertension, so those are the ones I know. The prosomide to reduce the freedom of the system, the amlodipine, pelodipin which has not been prescribed because of its scarcity, I believe with the right medication and adherence to treatment, the patient could be where they could become way better because I don't believe it's a permanent damage to the system.ok, it may not be completely reversed, but it can be prevented from worsening and wasting other tissues of the body.it has to be both sides, early treatment but also early administration

Interviewer: And so tell me about your encounter with these patients, when did you see the last patient? How long ago?

Respondent: Let's say last week because this week I have been out of the pharmacy

Interviewer: So it was last week? And was it a female....how did this patient present, was it a kid or an adult

Respondent: An adult, I think she was incultivated

Interviewer: So what drugs was the patient taking?

Respondent: I think it was transvelon

Interviewer: Ok and then...so you told me that most of the RHD patients are women, most likely not many years of school

Respondent: Yes, women and children

Interviewer: But do they tell you if they are working or not?

Respondent: No

Interviewer: Do you think that they are aware of the link between sore throat, acute rheumatic fever and RHD? Do you think that they are having a clue?

Respondent: Normally i don't think so because there has been screening and sometimes it actually shocks the patient, the person came in fine in the morning, she looks just fine and well, so just get done with this thing and go home, you tell them we may actually need to do another test, they are like what is wrong with me.I feel fine, I feel normal, I can walk home, am busy am walking so what are you talking about

Interviewer: And then you as a pharmacist, do they ever come to you to ask question that you feel that if you had the information about them, you would give them in this station?

Respondent: laughs, talking from my experience especially from my place here, natives from here, well am not from here, so there is a big problem from language barrier, so if they don't understand English, spending on them, asking questions, so usually you have to get the intermediary, you may have an interpreter or you ask them to tell you back in English, then you explain, then we get it back, so it's basically, getting back to the person. When you look at it on both sides but some of them by the time they come, they just want to get the drugs

Interviewer: And they don't ask questions

Respondent: Yes, unless it's you to involve them with the information, you tell them take these drugs take lots of water

Interviewer: So how do you explain those things especially now that it's not your native language, you have to tell the person to drink lots of water, do this, how do you do it, how do you manoeuver

Respondent: I have been borrowing extra man power

Interviewer: laughs

Respondent: I alwaysthat's why am friends with Jenifer, Linda and jafess

Interviewer: So in the morning when you start working

Respondent: In the morning I always greet them

Interviewer: They can help you?

Respondent: Yes

Interviewer: laughs

Respondent: Ok

Interviewer: And then if you look, do they ever describe their symptoms to you when they come?

Respondent: No, they just come to pick the medicine

Interviewer: When they come to you, do you get it but that's not the area, no I will leave that that is not for you. And when they come back do they present their empty packets to you or they take them back to the nurses

Respondent: I have not seen any coming to pick medicine with empty packet, not really

Interviewer: They don't come? Do you have a good sense of their follow up and their adherence to their medication?

Respondent: Since most of them are outpatient there mostly because the inpatients are given the interim report given when the doctor has prescribed, which medication have they changed from, so you can give a sequence, if the patient has been having ampicillin, then they went to ampiclox, then maybe the doctor prescribed genta, the Ceftriaxone, so at least you have a rough record of what was given and at how much, but the outpatient is mostly a single paper, laughs, the diagnosis, treatment and then they go, they usually don't come back, I know

Interviewer: Do they ever mention any barriers to getting care to you at any one point in this facility.

Respondent: I will not say they have communicated it out but I will cease to identify, somebody tries and prescribed the right drug not being on our reception medicine desk facilities, so here you know it a referral, we only provide a decisional ditties, the medicines are cheap, safe, it's effective, it's affordable and we always give to many patients, very many drugs fall under those brackets and they are first line, we always give second line and third line maybe the alternatives which are affordable and its like it can be better, if you give like spinalatol,you may never find it here, kavendilol,you will never find it here,

Interviewer: So some of the patients have to fend for it?

Respondent: Yes you may have to write a prescription that has maybe like four drug then you get only one like hypertension, that one has dephedipin and amlodipine, so if it's not one of those two, then it's up to you maybe plus captopril and phroximide

Interviewer: So how do you think we can overcome that, why is there fem medicine on.....

Respondent: It's a government facility, so you need to cater for that of the patient, that one I don't think its going to be rectified any time soon because we also at times, we run out of these essential medicine

Interviewer: You do?

Respondent: Yes

Interviewer: Like how long do you take before you get another stock?

Respondent: Usually they delay like depending if the drugs are ah...the contribution is really high and need is high, we and we stock, like when we have a delay, usually we request other facilities which is half way here to get them here, yeah, at many times we have gotten medicine from Kitgum, most times we have been giving medicine to Aduku an Barr and some health facilities

Interviewer: Have you reached to some extent where you spent like 2 weeks without any drugs and also maybe even when you asked for them to give you some, it takes some time to reach

Respondent when you ask for drugs from outside, the delivery is not more than a week

Interviewer: It can take a week or without?

Respondent: A week or within the week depending on the process because we have to write a letter, get it stamped by the director, scan it, send it, follow up on a phone, organise the transportation ,then you get it from there, so that's why deliveries delays

Interviewer: So what happens to those patients who comes within a week when you are still processing the drugs

Respondent: We tell them the drugs is still out of stock, that is the first thing, we advise them to purchase it from the nearest pharmacy before the come back because otherwise, we don't have much to do.

Interviewer: Ok, for those drugs that you basically don't stock here, on average for an RHD patient, how much do you have to spend outside to get the drug?

Respondent: On an average, I think if we don't have the drugs I have prescribed because If I give it a channelled look and also give it directive, hopefully without an ACE inhibitor laughs...like I have to record roughly ok, a minimum will have to be 15000/= because they are not going to take those drugs for like a month because it's usually for a short period of time

Interviewer: Wow!

Respondent: Yes

Interviewer: And then which other barrier do you think is...what else is hindering these patients from accessing care why do you think they don't come

Respondent: I don't want to say it in a bad way but most of the time people don't want to come to the hospital unless there is a problem, a problem they have noticed if I feel pain, pain is not going after 2 days, then maybe I need immediate attention. if I wake up feeling fine, I

can eat, I can walk, I can do all that, why do I need to go to the hospital, so that's why some patients have been surprised patient as they get shocked at their actions, their system is not exactly as they think it is. Yes so there is need for sensitisation and health awareness, telling them actually that this thing that maybe killing you slowly, actually be treated very fast and getting back to normal without you going through this documental effects

Interviewer: Ok, have you ever had about any sensitising campaigns around here about RHD?

Respondent: Not really

Interviewer: Do you have CME's here?

Respondent: Yes, every week

Interviewer: Every week? Have you had CME's on RHD management?

Respondent: No, the one we had was on ok there has been kind of on and on depending on how the hospital is but it's been on every Thursday, we had one on bespatter haemorrhage, we had one on mulateral sensation the last one we had was on sprain brain damage and how to navigate it and that's what we basically discussed

Interviewer: Ok so and RHD management?

Respondent: Maybe not yet, maybe it was done before I came in

Interviewer: before you came in?, so what do you think would stop someone from adhering to drugs, you give them the drugs, you tell them to take like 2 in the morning and 2 in the evening for 30 days, what would stop them?

Respondent: Sometimes it's a variety of factors really, one is the pill burden because the person you are giving 1 drugs2 X2 right that is four drugs already for day and so probably they have 3 drugs and one day there are probably 6 tablets, some of them have different frequencies, some of them is 1x2,others is 1X1,so he has to remember that ah...but that is also navigating what one is doing during the day, what kind of job he has, most of the locals here have subsistence sources of income ,selling food stuffs from the garden, tomatoes, onions, things go on basically, so navigating that and walking around the medicine. You start feeling feasible, usually if the medicine is home, so if you tell them to take 2X2, **you** have to set a reminder for them if really they are to do it

Interviewer: Why do you think some of them don't come back for reviews?

Respondent: Like I said before, the patient came, he was feeling fine **and** they are not noticing exactly the difference, so for you to notice, for him to exactly know the difference, it is for him to come back and do the review again, probably they sacrifice a day to do that, the other time we lost a girl ,so survival verses about spending a lot about their life because some it's frightening sometimes, so you have to choose to really, I am feeling fine but I need the medicine. Ok I need the medicine but I am not feeling too bad about myself, I really need to make that money, what should I really do? Go make the money, if you feel unwell again

Interviewer: Ok good, let's look at the local health system barriers here, which cases are not doing well for you?

Respondent: which one?

Interviewer: As you are doing your work here, what is not working well for you, what you would want to be involved, which area so that you can do your work well?

Respondent: There need to be..., as a pharmacist, I would say a fresher course

Interviewer: A fresher course?

Respondent: Yes, fresher course on the use of drugs especially in anti biotics because the way they are prescribed, are having, you have to re do the prescription because most of the time, we are in the pharmacy full day, Monday to Sunday, Monday and Tuesday is, we are have patients over load like after all the work is done, we have a long line and each ward they have like, they brought all the files at once, **so** you find medicine for like 12 files. Surgical has brought another 12 files, you have to go through all of them, **you** have a long....you want to leave this patient and get them done and get to go, you don't have time to think through what you are writing. So there is need to prescribe. So last week we actually had to move from the pharmacy to the ward to ask who wrote this because they wrote a prescription for, the diagnosis was without so much examinations. They made the diagnosis based on what the patient explained, abdominal breakdown, general weakness, then the person wrote Ulceration mild, as in how do you do ulceration mild just by mere looking, so the diagnosis was PUD plus PID then another person wrote Pluservicitis, then they wrote 7 drugs, five sets of them being anti biotics IV CEF, IV genta and doxycycline, Cipro, metronidazole, nystatin and omeprazole

Interviewer; But you are lying, is that true?

Respondent: I have the picture the support it because I had to take the picture

Interviewer: laughs, Wow!

Respondent: Yes, it's in family planning unit, you wonder are we treating the patient medically or we are trying to give them a condition so that they keep coming back because we can't prescribe 6 anti biotics in just one system, two of them being IV's so for that I had to mutually go there and ask who is treating and what is the criteria for treating like this because most of those actually out of the 7,omeparazole being out, so being 6,you could actually give 2 of them and the patient will actually be fine. Ok maybe if we need to supplement because if it was PUD and PID but you don't need to give 6 of them

Interviewer: Just out of curiosity, was that one a doctor?

Respondent: I was told it was a sister

Interviewer; Ok

Respondent: Yes

Interviewer: Wow!

Respondent: We had to rectify that on another day when you are very tired with lots of patients, you don't have a clear mind to literally do that, you just tell everyone to sit here, you do the rest if you are really tired, you just displace and until you discover with 1,2,3,4,5,6 anti

biotics for one system, what is the diagnosis, so you need to check, so there is maybe need for refresher course and the right treatment

Interviewer: So it's a refresher course, patients overload ah..., what else?

Respondent: The patients overload may not really be a problem or a hospital because the pharmacy is always there

Interviewer: How many people are there?

Respondent: In a normal day we have like two people there, two people managing

Interviewer: On average how many cases do you get, like how many?

Respondent: Managing the whole hospital, it's an inpatient pharmacy and also outpatient

Interviewer: So on average, how many **5 statute**

Respondent: In a day?

Interviewer: Yes

Respondent: That is interesting because I have never counted but it's over like 100

Interviewer: over 100

Respondent: Yes

Interviewer: Wow!

Respondent: Because the other thing is we have an inpatient pharmacy here and also the outpatient pharmacy but an inpatient pharmacy is free out of the hospital because they transferred it, so they have to go to the mental side so they give patients the prescription, they have to get out of this side, go round, then walk to that side and get the medicine, sometimes the pharmacy is also closed that side because patient's medicines are not there so most of them just come here. what is working here is also working for those ones from that side

Interviewer: Wow! Any other challenge you face

Respondent: The others is basically managerial, drugs being out of stock

Interviewer: The stock out of course

Respondent: Yes

Interviewer: ok and then let's look at the administration and leadership, what is your take on that? How have you seen the leadership here?

Respondent: In the hospital or in the pharmacy

In the hospital and in the pharmacy, let's start with your department, how is it running?

Respondent: Pharmacy department, it runs smoothly because you always know who is working and who is off and who is not there, in case he is out, they let you know, you may fill in for them because last week I was out of this supporting some things so someone had to fill in for me, so when I came back, we had to exchange

Interviewer: Ok, so how about the general administration

Respondent: The general administration of the hospital, we have the supervising pharmacist who always comes back and ask because during a normal week, **not** a normal week laughs, normally on a typical week yeah, it's the usual patients, medicines you give out but we usually have the internal evaluation, presenting complains, how the patient is reacting to this drug, there is always a problem with gentamycin and with the fresh batch they brought, people reacted to it abit but we had to try and find out. Some people reacted but then after doing some close observation, same people who were reacting to it were given the same drugs, there was no reaction, so maybe it was just spiking of the medication but same drugs, same dozes

Interviewer: Ok then, let's talk about the funding for health care in general, what is you take on it, what is your opinion about it, what do you have to say about it?

Respondent: The funding, well we actually try to do our best laughs, we actually have to do our best because we don't have everything that we possibly need or probably want but we have the basic to keep the hospital running, we are trying to navigate things laughs

Interviewer: And then for the RHD particularly, at least you told me that there are some you don't get, you only get the essential drug and then, so what can be done, do you know if there is anything we can do to improve the.....

Respondent: Well I don't know if this will work but probably they should do like a special clinic because you may do you checking and giving out the medicine but you could give the prescription like I told you that their business Is just selling food stuffs like tomatoes and onions, you tell them to go and buy the drugs that is costing more than 10,000 shillings, **they** will usually debate like why should I really spend this much money when I have major needs like food, transport that I need to cater for, if I don't cater for those ones, I may not survive but if am not doing too badly, so there maybe need to do a special clinic whereby boards should call their patients that they have their address earlier, that on this date and this month, we are going to do a review on all of you, then you can come with your medicine of their own, of course it may never be like this on the pharmacy and of course it's a standing policy for management of health care

Interviewer: Ok and then, when you look at your numbers in your department, how are you finding the numbers of people you are working with

Respondent: The staffs?

Interviewer: Yes

Respondent: The staff yes that is adequate enough with the numbers

Interviewer: You are fine with that?

Respondent: Yes

Interviewer: That is good to hear, and then the waiting time of the patient before they are worked on

Respondent: The idea is before the files come to the pharmacy, the doctor has done the review and like the doctor reviewed each patient because late in the evening and then it comes back in the morning because he has written everything and see whether to continue with the medication or he has improved or there is need to change his medicine, something like that. Now because there are very many, some times more patients in the ward and the ward round happens till mid-day, then they collect all the files at once, so you know medical wards. so depending on how soon the files come to you because if the file comes from a medical ward and you already came to your seat, we only work on them according to who comes first. Now for those ones who are emergency ward cases and the patient has come in, we first dispense that one then we can offer the files

Interviewer: Ohh and then how do you look at the health information or medical records here, how are the records kept here, are you happy

Respondent: Records, what do you mean?

Interviewer; If you have been working,

Respondent: Is it on point because its implication to treatment, it's very easy to retrieve it even when you are dispensing medicines like this ah...majorly aspirins ,we may not only record it in our books but also in the patients file .we always write IV, the date which IV was given and at what quantity, so even if you are working till Thursday, that person working on Friday can know this drug was given, it should last them in this number of days and the next time they should be coming back, it should be on this date

Interviewer: Thank you, good to hear that, any areas which needs improvement via information management

Respondent: Record keeping, maybe making it digital laughs, of course that will make it a lot, for the pharmacy, but in the store, it's already digital, so in case you want to retrieve anything, you just have to click on it and you get

Interviewer; So, let's talk about the heart failure drugs, anti-coagulation drugs, the BPG drugs, the diagnostics like the echo cardiography here in lira hospital

Respondent: In lira hospital?

Interviewer: Yes, how are the stocks?

Respondent: first of all, the diagnostic test, I don't think we have it here, they are mostly found outside there in a clinic close by where they do echo

Interviewer: The hospital does not have?

Respondent: They have been referred outside most of them

Interviewer: Most of them?

Respondent: Yes

Interviewer: Then the heart failure drugs, do you have them

Respondent: The heart failure drugs?

Interviewer: Yes

Respondent: we have a few drugs from the pharmacy, we have cardiac failure interblockers and ACE imputer, we only have a few of directives, and we have phroximide, receptive inter blocker, we don't have them yes sometimes we don't have anti coagulants

Interviewer: you don't have:

Respondent: yes

Interviewer: Do you usually get stock out of those drugs?

Respondent: yes once in awhile

Interviewer: Once in a while?

Respondent: Yes

Interviewer: And you told me that it can take like a week before you get another stock, have you had an incidence when even the other centers don't have drugs

Respondent: Yes, usually we monitor, we make an order based on the usage, So maximum stock, minimum stock, you have to have a good point, yes we are usually making a good point and we realised that the order would take a little longer than should have been the deliveries. We usually call the facilities by the time when we send a letter, you know, I want this quantity, what quantity they have to keep their facilities running and what quantity they will give you so by the time you make an order, you have a little to sustain you ah..to that point where you were organising the transport and stuffs

Interviewer: Wonderful

Respondent; So, you minimise time listening to them

Interviewer: And then if you look at the quality of care given to the patients especially the RHD patient, are you happy with it

Respondent: Well, am glad that they do the diagnostic test yes because once into treats and yes am really glad about that because by the time the patient comes to the pharmacy, you know exactly what is wrong with the patient

Interviewer: Ok, any missing....., is there any gap that needs to be improved on the care that is given?

Respondent: Maybe not necessarily about the care because maybe the general care information to tell, what the disease is about, what their chances really are because sometimes when you tell the person who has been taking the drugs for a long time that basically you are dying but have to keep them aware of it. You need to give the information to them. It should be good if you did that in the health clinic and give them all the information based on their questions

Interviewer: And then let's look at the guidelines, have you had the chance to look at the guidelines and protocols for RHD care, anyway have you had the chance to look at them?

Respondent: I haven't seen it

Interviewer: No? Would they be important to you if you have some CME's

Respondent: Yes, because it's a common condition compared to the 5 case every day, the frequencies is not so much

Interviewer: Do you think you would utilise this guidelines?

Respondent: This protocols, ok first of all..... In case you are interested, it's in place, you prescribe the right medication to the right patient in the right dozes, so the prognosis should be doing way better

Interviewer: We are about to finish by the way, let's look at the local health system do you think it is working for you here in lira hospital, what has made your work easy when you are treating maybe the patients, the RHD patients and the other patients, so what are the pluses for lira hospital that have made your work easy?

Respondent: well, we have good health workers, we have doctors, we have relations, we have detailed health care in place, we have the doctors, the nurses, the midwives, we have the support staffs and we also have the shifts in between, so when one person is maybe working, you don't get fatigued easily, we have people to help

Interviewer: Meaning that staffing is fine

Respondent: The staffing is fine

Interviewer: Then the administration

Respondent: The administration, they are quick to respond to queries and also find out exactly what went wrong and if the patient died, what was the cause of the death and what has been done up to that point, you would be doing best that you could. In case we are having a lack somewhere, how can we avoid it so that that incidence doesn't ever repeat, so that always goes out very fast and then the guidelines are not here

Interviewer: You told me that you don't have them

Respondent: On the ward recently there was a project and they gave out guidelines but with the British national format, actually with the latest version of 2018/2019, yes probably we need to sensitize people on reading them, they are there but they are not reading it

Interviewer: Ok just in case you want to look at the patients file, maybe on ward, would you find it easy to access that file or a patient who was seen like a week ago and then you need to go back and look at it maybe the things that were given

Respondent: Yes

Interviewer: How have you found that?

Respondent: Personally, it's very easy

Interviewer: It's easy?

Respondent: Yes because am part of that process, so if am to treat and diagnosing and am the one giving the medicine, I have to ask. so there are times I actually consulted the doctor because I worked on the patient given some of the diclofenac, the maximum dose is 150mgs

when the doctor gives 75 mg times 3 daily, so that is 75 mg excess that day, so I picked for the patient to come and see the next period to be able to come to see the doctor, so I called and asked, this patient you saw and you got this diagnosis and you gave this treatment, the problem am having down with the treatment is the 75 extra milligrams (mg), Was the pain so severe and why are you coming up with this ok, then he may tell you, it's a shorter course than what is required, I hope its just for today and then you will try to change it to a lesser doze

Interviewer: Ok and then the funding for the health care, is that one working for you here especially for the RHD patient since we are looking at RHD

Respondent: If it was for RHD we would be probably scoring negatives because we have roughly four drugs laughs. Yes the two of them being in the same categories and then the other one being a single category but for the health funding, we are trying what we can

Interviewer: Ok and then a little bit back to the health workers, do you have any specialists in RHD management?

Respondent: None that I heard of but I know doctors not specifically for RHD

Interviewer: Let's look at the perception of patients outcomes, generally do you think that they get the care that they need here when they come here? Do they get surgeries here?

Respondent: Yes they do

Interviewer: They do?

Respondent: Yes

Interviewer: Then for the RHD patients, can they access surgery here for those who fall sick

Respondent: Not that I know much about it but I don't think so

Interviewer: You don't think so, and then if you look at the quality of care that is given to the patients and their safety, what do you have to say about that?

Respondent: Well unfortunately by the time some patients arrive because most of the patients we have here are referred patients, that means they have been to the local clinics, probably they have guessed what their diagnosis is, some arrangements have been made on the drugs and they have paid for it, then the condition did not get any better, so they say, while we have tried what we can and the patient is getting worse and worse, just refer her to the hospital, so sometimes if not most of the time, there have been crisis management of what was given or the diagnosis they didn't find, sometimes it's completely the opposite of what was not completely related to what was done. So you have to rescue that and then you start a fresh, ok sometimes the quality of care is on and off

Interviewer; Do you have preventable deaths that have occurred here, the deaths that shouldn't have occurred?

Respondent: Yes, the patients sometimes are referred too late and what we can do is simply move smoothly because it has reached to the point of no return. Yes like for one coming and the BP is already hyper and they are already vomiting, sweating and unconsciousness, basically the best you can do is to check their blood pressure but again hold their crisis

Interviewer: But have you had deaths that shouldn't have occurred because of the care you have given here?

Respondent: Here if the patient could have been ours and he could have been on the ward and everything, the only reason we would probably have besides of course the natural cause, the person has already been distinct. **Yes** sometimes it is because of the belief system, even right now there is a patient on the ward, yesterday they refused, and the care taker refused the doctor to give the patient any medication for the whole day

Interviewer: Why?

Respondent: Because they don't agree on the medication, the medication is apparently making the patient weak or worse, so in case you do something in that case, it will be of course the care taker who will definitely say you killed the patient or you made the patient worse. But remember the patient will be in the ward and you are trying to get the patient on another level

Interviewer; So how do you deal with such cases, is it common or it's.....

Respondent; Yes it's not common but the ones that they will really give you a run for you money, they are staunch, so unless you really tell them sometimes, you have to remind them who is a doctor and why they are in the hospital

Interviewer: In the hospital?

Respondent: Yes, so in case you be on management on a daily basis, let us agree on a day, then you have no drugs because usually we have to sometimes start all over again, sometimes they may get complications

Interviewer: So, from what you have you have said like someone who has high BP, then they are coming, does that means that there are some people dying in the community honestly without seeking care in the hospital

Respondent: Some patients come to the hospital as a last resort, it has failed elsewhere, lets us try here, sometimes it's always the users, we have the emergency unit but sometimes we have the emergencies in another unit, like commits an abortion and the stuffs ,the patient comes and like in the gyn ward, someone tells you that I had pain in the morning and they have showed up about 8:00 p.m., so you wonder, so the whole day, what were you doing, yes, so you ask and to hear that they have been taking the smaller herbs, then you start asking, ok, that is all, what are complications that you should have been experiencing, it should have been done long time ago and then you see they have showed up

Interviewer; And then in your opinion, this is the last question, which are the two most important things ministry of health could do to improve outcomes of RHD?

Respondent: Sensitise the patients and raise awareness because personally I don't know much about it so I cannot imagine how much the community does know about it, then me as a medical worker, I don't know much about it unless it's a unique **local**, then they really need it too much, they will know about it but generally not so much about it ,so there is need to raise awareness, sensitisation **then** besides that, also on the drugs to treat it because the drugs that come, most of the treatment drugs are to treat hypertension also maybe because it's very

common but then RHD is not hypertension. So there may be a social distinction which may be solved much on their own if that is rectified, it should be fine

Interviewer: Wow, beautiful, thank you so much for your time, any question before we finish

Respondent: When should we get the guidelines?

Interviewer: You said?

Respondent: How can we get the guidelines?

Interviewer: The guidelines

Respondent: Yes

Interviewer: We shall leave that to our bosses

Respondent: Is there how we could maybe get it

Interviewer: No, we shall talk to our bosses because at least some of the bosses I think can do something

Respondent: Because we may not be able to get the hard copy unless we know

Interviewer: Thank you so much for that information, surely that is something that has been heard

Respondent: But the soft copies, some of us have the smart phones to grab whatever

Interviewer: She will give you the feedback with time because she is in contact with us, thank you so much

Participant ID	HW 003 – Lira
Age	■
Date	18th Nov 2018
Venue	Nurse’s room,LRRH
Interviewer	

Today is the 18th Nov 2018 rather and we are seated here in the nurse’s room at LRRH. We shall give you 003, health worker 003. So doctor before we start, I just want to know more about you

Interviewer: How old are you?

Respondent: Am ■ years

Interviewer: ■ years?

Respondent: Yes, am an ■ doctor in lira regional referral hospital?

Interviewer: And how long have you been working here?

Respondent: I have now worked here for ■

Interviewer: ■?

Respondent: And I am here for ■

Interviewer: You are here for ■?

Respondent: Yes

Interviewer: Ok and so when did you qualify, when did you finish?

Respondent: I finished in ■

Interviewer: In ■?

Respondent: In ■

Interviewer: ■

Respondent: Yes ■
■

Interviewer: ■

Respondent: In ■

Interviewer: ■

Respondent: ■

Interviewer: And will be number one

Interviewer: laughs, ok, good to hear that and then let’s look at the demographics of the patients that you see, what are the common illness that you have treated since you came in?

Respondent: Since I came in?

Interviewer: Yes since you came in

Respondent: Since I came in, right now am in the main medicine ward, but I also go cross to the female medicine ward and sometimes at the emergencies, yes to look at the distribution, disease distribution, I see more of liver disease in the elderly people, liver disease is very common, hypertension, **PUD** also being very common but in children I have noticed RHD, RHD is one of the problem in children and sickle cells disease, those two stand out

Interviewer: These two stand out?

Respondent: Yes, in children although sickle cells is more but we have seen common cases of RHD in children, actually on my very first day here, I got a child with RHD and I was running around to see how to get help then I had to do echo, I had to do what....., those things are not done here at the hospital, **then** I noticed there was a project here that was doing that and that helped

Interviewer: Ok good

Respondent: But subsequently I kept getting in touch, but common among children

Interviewer: Which other age group do you see with them?

Respondent: RHD?

Interviewer: Yes

Respondent: RHD in early adulthood, I have seen it in 22, twenties early, I have not seen it in the elderly, middle age adults, I have not yet seen it there

Interviewer: You have not yet seen it?

Respondent: Yes

Interviewer: Ok, before we get there but we are just on track ok so let's talk abt about the, your RHD training and management, have you received any training during school?

Respondent: At school as one of the topic

Interviewer: Yes

Respondent: In internal medicine

Interviewer: Yes

Respondent: We went through many cardiac conditions like RHD was one of the Topics, that we came across, also during the **affluent prayers**, we would actually come across patients

Interviewer: The patients?

Respondent: And we would be taken through but not as a special course or a special training but the knowledge I was using was basically what I came with at school and then with the help of my supervisors around but am not trained in the disease in particular

Interviewer: Ok so does that mean that after your graduation, you have not yet had any training?

Respondent: After my graduation of course I haven't

Interviewer: Not yet.....

Respondent: I had a period of about 5 months where we were just waiting for internship, you get it, in that period, there were trainings with the ministry of health which I went through but the one I went through was something to do with haemorrhagic fever, Ebola management, Marburg and the rest, those were our training CBC infections control

Interviewer: Right

Respondent: Yes

Interviewer: So you have not had any training on RHD?

Respondent: But on this, no...

Interviewer: Ok

Respondent: Not yet

Interviewer: And then in a day, how many RHD patients do you normally, typically see?

Respondent: If am to say in a day, on average I can say maybe one

Interviewer: one?

Respondent: Yes ok so where I am, I can see only one, so in a week, you could say maybe 3 also

Interviewer: And then are they usually outpatient or inpatients?

Respondent: They usually come as referrals from health centers, you know if their symptoms worsen, they have tempted to be treated and they fail

Interviewer: Hmm

Respondent: But when they reach here, we actually realise they don't come with the diagnosis of RHD, they come, they come with you know somehow being managed with malaria, malaria but not the coughing, respiratory tract infections, they come when they are badly off, doing badly so they come here, so it's usually from here that we notice, we are dealing with RHD here. I have not yet received a patient who has come with RHD as a diagnosis from down

Interviewer: You have not seen?

Respondent: From the health centers, usually we discover from here that we are dealing with RHD

Interviewer: So what are the normal, usually which symptoms do they present to you when they come?

Respondent: They usually present with high fever, you find they usually come with high fever, tachycadic, you know breathless, some of them are in failure already, heart failure already

with difficulties in breathing, not so much coughing but with difficulties in breathing, you know with heart failure with its symptoms, difficulties with breathing and some cough there but yes, also some of them with **articulation**

Interviewer: Ok and then let's look at what you have been taught, what is your understanding of this disease? RHD?

Respondent: From school, my understanding right from class is that RHD is haematological related and to begin with what professor used to tease us was that this problem is the problem of the third world countries, yes, it's the disease of the poor, they get respiratory tract infection and they may get neglected or don't treat it aggressively and they end up getting the problem, the problem comes from what we call a genetic mimicry, the organisms usually streptococcal, that has the ability to induce the immune activity in the body, that immunological activity may result into the formation of anti-bodies against the organism, however these anti bodies or the organisms, they target, these targets on the organism may resemble some structures of the body system, one among them is the valves, could be the kidney, can be the joints, so at the end of the day, these anti bodies end up attacking both the organism and the body structure, therefore leading to RHD, with all its symptoms

Interviewer: Ok and then could you be, are you aware of the link between the sore throat and RHD?

Respondent: Yes, usually because the streptococcal is always along the respiratory tract, so it starts with the throat, it starts with the throat, if not treated well with proper anti biotics, it can translocate into the circulation, then from the circulation the issue now starts in the immunological relations

Interviewer: Were you told about how to prevent RHD

Respondent: Yes, we got to know that sore throat should not be treated, you know reluctantly, it must be treated aggressively with proper anti biotics but given the system oh...of course we would, we would with a sore throat, and we would think of sore throat, we would do microbiology of the cell but usually treat our patients systematically here die to exhaust irritations, we can do the microbiology test to find out which organism exactly we are dealing with, then we must prefer ah.... broad spectrum anti biotics could be good like broad spectrum respects anti biotics say amoxixaslin clastic as to be able to cover maybe as our first line **but** like I told you in my first statement, **it's** the disease of the poor, in most cases these drugs must be expensive, a little expensive and people just end up with the local herbs and they think it can go with that, then they end up being a problem

Interviewer: Do you know of any local herbs that people around here normally use for sore throat?

Respondent; Here they normally tell me they boil, they boil lemon leaves, then squeeze in it also the lemon, make some coco just to try and sooth the sore throat and cough of course I don't know if it works for them but it just seems to me as if they end up with us to the hospital

Interviewer: Do you usually get patients coming in with sore throat? Is it a common tradition that is here?

Respondent: It is not, it's not usually for patients to come complaining that they have a sore throat, they come when maybe I don't know maybe because this is a regional referral hospital, they become when maybe its pneumonia, they are coughing badly they come with difficulties in breathing and they have tried with their cough elsewhere, it has progressed away from sore throat

Interviewer: So why that sore throat is is not taken like seriously?

Respondent: One, I think people have many problems that they try to ignore health conditions, they would want to try and pay attention to other things, they start paying attention to health situations when now the condition is worse but usually I think, I think according to their responses because usually we get patients when they are very sick, they come here when they are really very sick and when you ask them, they tell you how they have spent a long time home without getting help .one of it is not attaching much care or concerns to health but also the issues of economic problems but in most cases when you ask them, they tell you they come from very distant places, the distance from where are residence to the hospital usually it involves costs to transport themselves, am sure it's one of the problem.

Interviewer: The issue u know going to the health Center and you don't get the drugs, these drugs they rarely just buy, sometimes they don't get the drugs also available in the hospital day and they get reluctant to go to the health Center or to seek care but if you don't have the money and you know you are going to hospital and what you need is not there, sometimes you end up trying local herbs, they delay to seek care

Interviewer: Ok and then talking about drugs, if you look at this facility here in the hospital, how are stocks?

Respondent: Stock for RHD drugs, antibiotics are available, we have anti biotics ciproproxline are available. when it comes to others because when it comes to RHD, you are going to have cardiac issues you are going to have issues with inflammation, So there is too much limitations in terms of the availability of drugs, drugs are very limited, very, very limited like if you look at the management, you may need a steriat, you may need a steriat to manage to clear the patients, I have not at any time ushered a steriat since it's never in and they are usually not in stock ,Asas you might just need an Asas or aspirins, also its always out of stock because those are the first line drugs that get always out of stock, I don't have the explanation for that but they are usually not available

Interviewer: Stock out!

Respondent: They are always stocked out, of course if you want to handle, if you have issues of cardiac that you want to do, you are limited to a particular formulation, if you want your, I you want your... if you want your Vito blockers, you may have only eplocanol available other than these kind of drugs are still a problem here, when you are to manage RHD, you need a whole package to manage this situation, so they have to buy, you have to ask them to buy and there become is a problem, go buy they will tell you they shall buy, you come back, and they have not bought No money to buy, the patient is detoriating, the joints are getting inflamed, the deformities are beginning, you get it! The fevers are running high, you, you try with your anti biotics, you try it but inflammations are flaring, you get it! So it's a challenge

Interviewer: Now what can we do?

Respondent: Now I think it start with how to empowering people economically would be the way to go but of course it's a long, long way to go but in like a short term, arrangement maybe you would encourage that the hospital be stocked with all the necessary drugs because they are not even very expensive, somehow in most cases like if you want a steriat, usually like cortisol steriat, they are not usually very expensive but you find this people are already broke, they don't have money to buy so we can stock them ourselves, vendecine of course is there, vendecine penicillin but it's also out of stock in most cases, it's also not expensive out there

Interviewer: Ok, thank you. How, during your school years were you taught about the treatment option for RHD, of course I have heard you talking about the drugs

Respondent: Yes the different options?

Interviewer: Yes

Respondent: You see we were taught ,of course we answered those questions, we know the root cause now, we want to attack the bacteria, of course now in the heart the bacteria is not there, it's now the anti-bodies against so we give vendecine peroxyaxis monthly dozes of vendecine depending on the ages, of course now we treat the symptoms that are coming with these anti bodies deposited, yes we can deal with the bacterial infections with anti-biotic broad spectrum preferably with penicillin best interactors and then we deal with the inflammations caused by the anti-bodies. we tend to, since we know there is anti-body production, we want to supress that process so we use cortisol steriat to suppress them and give ASAS for inflammation and the fevers we try to bring it down to respond and if there is candidiasis, we go and give them, if there is a heart failure, we give them heart failure arrangement inter blockers Castrol blockers, so that we try and lower the pressure and also reduce the heart rate

Interviewer: Ok, thank you, so what is your understanding about the long term prognosis of RHD? , looking in your own understanding

Respondent: My own understanding is that if managed properly and effectively progress is good, prognosis is good, we can reverse the articulation, we keep giving them this anti-inflammatory, the cortisol steriat also for some times, also as we do physio therapy, they will always get up and with our monthly Benzathine Prophylaxis, we try and prevent the organisms from continuing to grow. yes they probably, the Benzathine penicillin, yeah, the prognosis is not very bad if managed early, if the heart, if the heart is not badly affected but of course if we delay and the valves are now badly damaged the heart is badly damaged, then the prognosis might not be good because it might involve that you do valve replacement or transplant which is not a good thing, it depends on when you come in and how far the extent of the damage to the heart valves

Interviewer: Ok, wonderful! Then let's talk about the encounters with RHD patients, do you remember the last patient you worked on and how long you are....

Respondent: Right now I still have one, I think I have two, Right now on the ward, you saw it's still a fresh thing

Interviewer: Yes

Respondent: And I expect anytime

Interviewer: Yes, give us a picture of how these patients presented and

Respondent: These patients presented at emergency department with a very high fever, uncontrollable cough, and cough with joint pains, generally weak so at the emergency, the person who was there made a diagnosis of pneumonia and the patient was actually referred with pneumonia. So being on the ward, I received the patient and he is actually 15 years old and they were coughing, they were breathless and I immediately first put him on oxygen, then when I started my clinical exams. I saw this patient was remitting a joint criteria for rheumatic diagnosis of RHD, they already had ah...hydratory hytheritis with even spinal deformities, very high fever, the cicardia, the heart murmurs were already there, so I called for help as I told you, echo here, we don't have as a hospital, so I came, asked for help from the project. Then we did the echo, first we did a throat swap, the rapid test was positive, so I knew I was on the right track, echo was also significant yeah so then we sat up together, we started the treatment, and the patient started improving. Now he has improved, what he is left with is the physio therapy not yet, what am left with is the physio therapy then I discharge him

Interviewer: Ok, good to hear that. then, so you said you mostly see children with RHD

Respondent: Yes, Mostly children like between 10, ages between 10 and 20

Interviewer: and 20?

Respondent: I have seen most of them. I think there was only one who was less than 10 years because night duty is always long **but** mostly between 10, I can recall 3 with 15 years, 14, and 15

Interviewer: Ok

Respondent: Yes

Interviewer: And then could you be knowing if they were in school or out of school children

Respondent: They are in school children

Interviewer: They are in school children?

Respondent: **They** are actually in school children

Interviewer: Ok and then do you think they know the link between sore throat, acute rheumatic fever and RHD

Respondent: That is where there is a problem, there is so much knowledge gap in terms of health, they don't know, exactly they don't know at all, When you ask them, have you ever suffered a sore throat? They will admit it to you, **did** you treat, no it went, it went but now finally am getting cough again, yes but there are knowledge gaps. It's somehow the knowledge gap, they don't have that knowledge

Interviewer: Ok, and for them, what symptoms do they describe to you when they come?

Respondent: For them the symptoms they describe to me is the joint pain, **general** body pain, they say general body pain and stiffness in the body, stiffness in the body with swellings, yes and cough of course fever is getting high, they try with anti biotics and then they go down and being breathless, failure to breathe

Interviewer: So generally are they following their follow up and adherence to the things you tell them to do and the drug taking?

Respondent: The follow up according to me I think its zero, there is zero follow up according to me, ok as me , I have never tried to follow up because, we need the scope of plans, so and I don't know whether there is follow up elsewhere

Interviewer::But do they adhere when you talk them

Respondent: Then adherence, we try and encourage them at the discharge to try and adhere but I can't ensure, I can't know what happens when they go home, especially that these drugs has to be bought, so I don't know, you write but I don't know whether they buy it but I think they buy it because I have no seen re-admission yet in this period of two months, I haven't seen that

Interviewer: You have not seen any re-admission of RHD?

Respondent: Yes

Interviewer: So what sorts of barriers do they commonly state, barriers to getting care that they need, what do you think stops them from accessing the care

Respondent: The barriers start with the economic status, distance from where they stay to the facilities **and** then you know poor economic status, funds to put into transport, buying drugs and the availability of drugs in those centers is another problem. In those centre they have very, very limited and they get out of their stocking

Interviewer: And then when you are discharging, am sure there are certain things you tell them to do or not to do

Respondent: Yes

Interviewer: Right, do you think they obey them?

Respondent: They rarely, they are but you see laughs. I can talk to you, most of the patients have been found to be patients of the very low class status. Even their ability to comprehend the information is very little, their ability, their capacity to understanding what you are talking about is very, very limited because before you choose, and you decide to discharge them. They want to go home, yes I don't but you try to explain to them because we want since the ailment comes with articulation problems, it requires continuous you know physio therapy, rest and prophylaxis treatment, yes, continuous treatment of any other symptoms that comes like I told you the knowledge gaps like their ability to understand. I have not tested it, I have not gone to do research to find out whether they adhere to some of these but in my own thinking, in my opinion, I think they neglect, they don't get, they don't find time to pay attention towards this disease.

Interviewer: So when you give them appointments ah... I don't know if you have given some to come back maybe you have been here for two months?

Respondent: Yes, 2 months

Interviewer: 2 months? Have you had to give any to go back for appointment?

Respondent: Yes

Interviewer: How was the turn up, did they turn up?

Respondent: Yes fortunately they come back

Interviewer: They come?

Respondent: Definitely they come, if you stress to them the importance of what you are telling them, they come back, you write it on their discharge form,

Interviewer: You have just answered what I was going to ask that why do you think they come back for their appointment, so it is stressing of the

Respondent: It's the emphasis

Interviewer: emphasis that you put on?

Respondent: Yes

Interviewer: If you attach a lot of emphasis?

Respondent: Yes

Interviewer: They will come back

Respondent: Yes they will come back

Interviewer: What else do you think motivates them to really come back?

Respondent: To really come back?

Interviewer: Yes

Respondent: You know the horrific status you find the patient usually at the peak of the disease, they get helpless and you think yes, we are losing the patient and now seeing this patient come back to life and able to live, walk, I think that also sends signal to them, so they want to listen to what we tell them to come back

Interviewer: So when they get better, then they are encouraged to come back?

Respondent: The only thing I told you, yes, they are encouraged to come back, the only thing I am not sure about is the day today information you give them that daily dozes do this, give this physio therapy, give these drugs, go buy them that is what I don't know whether they do but come back, they do come back

Interviewer: So those that come back, have you encountered, why do you think some people don't come back for their appointment?

Respondent: Sometimes I think because of transport issues

Interviewer: Transport issues?

Respondent: Yes, issues of no money to transport the child and even when they are here, they try to make call to fund their bills, what they eat and some drugs they buy, so at the end of the day when they get back home, it becomes a challenge given their status, I think that is one of them. I don't want to attribute it to the negligence but I think I want to attribute it on the capacity

to come back and take care, that is why am telling you that even the day to day care, I think it becomes a challenge because I think there are usually large families out because now others also have to eat, what to drink and other basic needs. They tend to ignore health issues, so basically and the late presentation in the hospital

Interviewer: You said they don't really take health a priority that is why they come and present late?

Respondent: Yes, because I think they try local remedies, because they try chances, they give it to chance, they delay to present and probably shared negligence to health related issues might also be one of them and then also the "big animal" 'poverty, poor economic situation that is eating us

Interviewer: That is eating....laughs

Respondent: Yes

Interviewer: Ok and then let's look at the local health system barriers here, what is not working for you on your side here in lira hospital, you want to do this but you are let down

Respondent: sorry to say this but investigations are so limited, investigations are so limited here in lira hospital. Investigations are done outside the hospital from private settings and yet we also discovered that not all private facilities give correct results from the investigations, so you can't investigate properly

Interviewer: So you said that you don't have, you don't have a ECG machines?

Respondent: Now here if I am to point out, the only thing here is the ultra sound and x-ray. for a CBC you can't, I can't do a CBC within, we can't do echo, I can't do CT, I can't do....of course CT is now too much to ask but I can't do a CT,I can't do any electrolytes, you get it! I can't do any microbiology related investigations. You don't think of a culture or of chemistry or any other things, I don't think even just of a gram stain of course I can't analyse urine laughs, so I don't know why those challenges are persistent but that is the picture, what I can only do is an x-ray and ultra sound, those two **are** not enough to investigate the patient and they are far from helping the patient, so that's one of the barriers, another barrier to help would also be the series of those I listed. Being a regional hospital, people come from very far and when they come here, they find it hard to maintain themselves, you want to keep the patient but the attendants have nothing to eat, they have nothing to help them, so that becomes also a barrier, that becomes a barrier coming from the side of the patient

Interviewer: ok

Respondent: Patient's side

Interviewer: In Mulago, patients gets some food, Are patients here given food in the hospital?

Respondent: They are not given food, food is not there

Interviewer: There is no food, you are to cater?

Respondent: There is no kitchen working because even me, I don't eat food here

Interviewer: laughs...even you, you don't eat food?

Respondent: laughs.....

Interviewer: laughs...I thought it was across because like in kawempe where I work, you get food

Respondent: We don't get food here, we have been trying with the director on that, we can't be hungry

Interviewer: So when you look at funding for health care

Respondent: Funding for the health care I think it's still far below the belt, funding for health care is still below

Interviewer: And then for RHD care?

Respondent: For RHD care becomes very serious, indeed it turns out to be like a luxury, they will not because if they cannot provide those others, food and the rest, singling RHD might be a long way to go, for health, for the hospital and for the ministry or for the budget ok, to take care, it will be a challenge, to me i think so unless your justification but I see it as a problem

Interviewer: And then let's look at the administration, how do you look at it?

Respondent: Administration, I have not paid much attention to the issues of the administration much in this period of 2 months. But so far I see administration is there, there is no gap, I don't see the gap because I see the director is around, all the offices are occupied ,the SPNO is there, the heads of departments are there ok so they can be there. What happens in the administration is not just people occupying the offices, work going on and that is a sensitive part that someone had to talk about

Interviewer: So in case you need something to ease your work and you raise the issues to the administration, what is the response?

Respondent: What was the response? The response is simplified to lets work within our means, its simplified to that level, just we use what you have available, what you don't have, patients can go do it.if they cannot, if the **miss schedule** are not within, you refer to the national referral and that's why we can refer patients just for INR to Mulago with far bleeding issues

Interviewer: Ok taking it to a higher level leadership within the district do you see any concern for the health issues?

Respondent: At the district? Yeah, at the district I have not yet broadened my...,I don't know because I have only been here for a short period of two months, in a short period of time to know how they engage at that level. I have not yet taken time to study their engagement and development about our matters

Interviewer: How about health information system, medical record system at this place when you look at it, is it working for you?

Respondent: Yes, we have a record office, let me show you how it flows, we have an outpatient, we have an emergency department, so from the outpatient for these requiring emergency, management and possible admission, they come, they open for them a file from record office. Now at the record office, **all** patients' information is kept there, it's usually hard copy and I think digital computer

Interviewer: You call it digital?

Respondent: I think they have a computer system

Interviewer: Ok

Respondent: Where they keep some information about the patients, what I know is we have a record office where patient's information are

Interviewer: Just in case I wanted to go today and I just look at the RHD that they saw from January- November, will it be possible to get the information?

Respondent: That needs a trial, we need to try the system, I need..., I haven't checked but I need to find out like I told you, office can be there like this record office but that does not be the thing there but the activity there, are they going on, are there, is there capacity to do the right thing, are people doing the right thing, that detail I need to find out but for the structure, the organogram, I see the structure is there, I don't know whether it's giving, its doing what it's supposed to do

Interviewer: Why I'm asking is because we find some health facilities, you just reach there and then you have the boards

Respondent: Boards?

Interviewer: Statistics

Respondent: Statistics of this.....you are right, those statistics, that feedback, that information is not available, you cannot go to my office and you are able to see on boards the disease patterns or distribution of the disease and easily. I don't know whether that information is at the records office but at my level, it's not available

Interviewer: Ok, do you have, could you be having guidelines and protocols for RHD care here?

Respondent: Not yet

Interviewer: Not yet?

Respondent: Not yet

Interviewer: Do you have CME's here?

Respondent: We get here CME's

Interviewer: Have you attended any of the RHD training?

Respondent: Not yet, the CME's we have attended are mostly to do with gyne, to do with gyne issue and other emergencies, RHD not yet

Interviewer: Not yet eh...? Will you find them important if at all?

Respondent: Yes, it would actually be very important to give capacity to health **workers**, start with the health worker capacity to have knowledge on how to manage it and also how to maintain the patient. After the treatment, how to keep the patients, it's very important if we could have the training

Interviewer: So would you go for having the protocols for RHD and guidelines?

Respondent: Yes, but do you think, I would go for if you asked me, I would go for CME's to create, to increase, to raise these people's suspicion index, you need to raise these people's suspicion index because I have found, I told you of one who went through the emergency department and reached to the ward and he was getting treated of pneumonia without anyone thinking of RHD, that shows the knowledge gap, so you raise the suspicion index then you bring the material for people who already suspicious of the disease or is aware of the incidence of the disease. Then materials will help, so the protocols are there, how to manage, the outcomes and how to advise these people subsequently after hospital stay, now at home, how they should take care of themselves, home care and the rest of it, those ones now would benefit those who are already with the highest suspicion and are knowledgeable about this disease. so if you asked me, CME's first then eventually protocols and guidelines, would be coming

Interviewer: Ok did you talk, do you have ah...how are your stocks for heart failure drugs, anti-coagulations drugs and then the BPG

Respondent: Heart failure drugs especially congesting heart failure?

Interviewer: Yes

Respondent: We have stocked phroximide, we are stocked with phroximide but that goes along with **spironato**l but when it comes to hypertensive drugs, they are usually not available, they are out of stock. I have always, a part from **propanol** as the inter blocker, the rest they have to buy

Interviewer: Why do you think that it's always like that?

Respondent: I don't know, I don't know, I think, I think it still goes back to the budget allocations to help, most of the drugs we have are for the basic care, basic care, you know for the serious treatment, patients have to go and buy,

Interviewer: And buy for themselves?

Respondent: Yes, for instance the hypertensive drugs are hard to find in the pharmacy

Interviewer: In pharmacy?

Respondent: In the hospital pharmacy, it's very hard

Interviewer: So looking at the system here, the local health system here, what has worked for you?

Respondent: What has worked for me?

Interviewer: And why?

Respondent: And why

Interviewer: Yes

Respondent: Ok, as like I told you, as an intern doctor, what has worked for me is my working relations with the senior staffs and the supervisors, it has worked for me because I make decisions that are verified, some cases corrected and for me that works for me **and** also the

drugs for basic needs are always available, in most cases, **they** run out for a short while the deliveries are made, when they are made, at least they are sure of having basic needs which are substantial to buy anti biotics to start with as you think of out there yes and space because with that space you can do your work

Interviewer: Ok for the things you have mentioned, what has worked for you?

Respondent: At least after basic education, the relations with the staffs

Interviewer: How about the numbers, are you comfortable with it

Respondent: Ohh! That is one of the thing that has not worked for me, the number are soooo big but with limited staffs and so ok,the numbers are very big, yeah and the staffing is small so the patient –doctor ratio is very small, sorry, it's so huge, the other way round, the numbers are big

Interviewer: You said there is a gap in the staffing?

Respondent: There is a very big gap in the staffing

Interviewer: **Where** specifically?

Respondent: Especially the doctors, the number of doctors is very, it's really very small, the nurses can be there, they get help from the nursing students, they can administer drugs but when it comes to the real clinical care of the patient, you need a doctor's hand on the patient and you see when the numbers are big, you try to reduce on the number of time you spend with the patients and that causes a lot of problems in terms of making effective diagnosis and care to the patients, so you try to distribute your time to many people, you see this one briefly, they talk to this one faster, faster, you pick what you can do to save them, you start with urgent situation, you be with them, you don't pay much attention **or** give enough time thoroughly to get the information that help the patient out of the problem leading to a longer stay in the ward

Interviewer: So in case of the RHD that are, have you ever referred any?

Respondent: I have not yet referred RHD patient because the ones I have managed, I have been able to discharge, so I have not yet

Interviewer: So do you have any guidelines in this on how to refer them?

Respondent: I haven't gotten the guidelines

Interviewer: No guidelines?

Respondent: I am still using my piece of knowledge

Interviewer: Would you find them important

Respondent: Very important, very important to have these guidelines because you know guidelines help in simplifying on time you take thinking of what to do in this situation, you just have the outlines there and then you tailor the information very accurately to the patient, also your approach is well tailored, it guides you

Interviewer: Do you feel satisfied with what you went through?

Respondent: It is a struggle, it's still a challenge

Interviewer: You know why we even ask the health workers this question

Respondent: Yes

Interviewer: It's because it will require an integration just in case ah...the health workers thinks they are giving enough care, laughs, time and the other side the patients cannot

Respondent: If I cannot do a follow up, echo, I cannot do follow up, ECG'S, i cannot do you know do those other investigations to make sure the patient is out of danger then what is my right? I can't be satisfied that I have done enough. I only base on the symptoms, the resolutions of the symptoms, ah... you go give us space

Interviewer: Can patients access surgery here, RHD patients?

Respondent: No

Interviewer: It's not done?

Respondent: No, this is a referral

Interviewer: laugh

Respondent: You can IO's, sometimes we can have a dysfunctional theatre and cannot do IO's here

Interviewer; laughs

Respondent: We have not touched the heart valves, so it's far, it's far from that

Interviewer: Do you think there are some deaths here which occurred that surely would have been prevented?

Respondent: Very many because sometimes we can have very many cases that patients die of anaemia because we don't have the blood bank. Patients die because they cannot afford the good antibiotics to...I give anti biotics to treat them, patients die because doctors sometimes are out of the station

Interviewer: Ok last bit that we are looking at, let's look at the perception of the patient's outcomes, generally do you think they get the care that they need here?

Respondent: We struggle with that aspect, patient satisfaction like I told you, you are the only doctor running around, the patients are looking at you, the whole day you are there you don't have time to see them, after maybe after one day, I think patients satisfaction is lacking' I don't think they are satisfied

Interviewer: They are not satisfied?

Respondent: But as long as the symptoms are resolved they will feel happy.

Interviewer; So do you feel that they get the treatment that they need before they go away

Respondent: They get the basic

Interviewer: laughs, they get the basics?

Respondent; laughs, they get the basic treatment, I think they are not getting enough treatment that they deserve, even if they get it ,they delay in getting it but at the end of the day ,whatever they get ,it is helping them to go home

Interviewer: Ok, so what do you think causes it?

Respondent: That question actually would be best answered by those patients

Interviewer; By the patient?

Respondent: Yes, do you think...., do you feel, that is a perceptible because for me now, when I see you, yes, you are good enough to go home. I think you have gotten already what you need but the feedback should also be there and the drugs are available or nurses are not available to extend to the immediate needs of the patients, patients die because the required drugs cannot be found anywhere within like I had similar case, a severe hypertension, hypertensive crisis patient who could not get glabeterol IV and we could not save him immediately or even night hour, so there are so many deaths that would be prevented

Interviewer: That would be prevented?

Respondent: Preventable deaths occurring but not to allow, we try with whatever we have to save lives

Interviewer: How about the patient's safety, do you have any concerns about their safety?

Respondent: Safety is broad, is it security, or it is health?

Interviewer: Yes in health

Respondent: How they are managed, the safety I would say provided the doctor is available **and** the doctor is knowledgeable, the patients are safe. For now I would think really that the patient are safe that is the reason they kept coming, flocking **because** they go back discharged some of them, **the** safety is...i think is at least above the belts, its abit fair, they feel safe

Interviewer: Ok, do you think that there are some patients who have died in the community without even stepping into the hospital?

Respondent: There are some deaths of arrivals, it is also in big number, I have also realised that private clinics admits patients when they see the patients are about to....they are failing to handle the conditions, they send patient here to die, **they** delay them in the private hospital

Interviewer: How about the RHD patients in particular, do you think they have some....

Respondent: RHD's I haven't, I haven't heard of death on arrival **or** death due to RHD yet in this period of two months or maybe as time goes on but not ,I haven't

Interviewer; what is your opinion? Give me two most important things ministry of health should do to improve on RHD outcomes

Respondent: Two things! RHD must be considered as a priority, it affects the young people, it affect the young generation and given that the country is aware, **the** larger population especially the upcountry is a poor population, once we attach that kind of importance to the disease, then we attach the budget specifically for RHD and when we are attaching the budget to the RHD, It means we start with the investigations at the hospital level, we should be able

to investigate fully so therefore we must have all the services to investigate and then treat, stabilise the patients, so we look at the arrangements required, the drugs that we need for RHD and therefore that means we will have a department but RHD problems or cardiac issues or RHD finally where we can make it greater but not that it's stopped, so that it is about within internal medicine that handle the disease, that is on the side of the government but also on the side of the health workers now, you asked for two right? , you need to empower, we really need to empower the health worker's ability to manage RHD clearly without fumbling so that the diagnosis should be as fast as possible, I told you the prognosis would depend on the extent of the damage to the heart valves if this patient is really to do well, to overcome the world, the damage, the joints and sometimes it can even damage the kidney, so the capacity to diagnose requires the vicious circle of training of CME's and protocols, then you will be able to manage

Interviewer: Last one, how about the other conditions, when you talk about RHD, how can we improve the outcomes of our patients

Respondent: On a broad scale, it's largely a political will to attach all then budgets and importance to health must be prioritised, healthy community is a wealthy community, yeah so with that concept, it should start from the budgeting, **the** Maputo protocols of 15%,really was it Maputo or the Nigeria-Abuja, I think it is read by Maputo conference attaching 15% of your GDP to health is one thing that will address the insufficiencies in terms of facilities to use, to investigate, to treat, to counsel, to staff, to staffing all that requires a budget, you get it! Then now supervision, we need supervision in those hospital and supervision should not only be internal because internal can easily get compromised ,supervision should also control out, people should know that anytime supervisors and external supervisors can come and they want to know what is going on and people can be punished if found on the wrong side, so with budget on and the supervision ,because budget will address many things but if there is no supervision also, you will be sorry on the rock, both laughs...

Interviewer: Ok thank you so much for those ideas, we are going to put all these together with the rest we have got from other health workers and other groups and then we shall definitely forward that information to the concerned people to see how our patients are treated better and those who are not yet patients, then they gladly Care for our patients, any questions before we close?

Respondent: I was reading through the concept yes the project, this is a project?

Interviewer: It is a research

Respondent: It is a research project?

Interviewer: Yes

Respondent: How long is it?

Interviewer; We have two hands, she is directly handling quantitative and the qualitative is on, it might go on because we have four district to cover, we are going to Mbale, we are going to mbarara, we are going to Kampala and we have stared with lira, so we might run for the next one year and a half

Respondent: So when do I get my feedback because it says that there will be a feed back?

Interviewer: We will give feedbacks in case there are findings, new findings that would be having an impact on your work

Respondent: Ok

Interviewer: So that comes after we have analysed all the data

Respondent: That is after one year

Interviewer: laughs...one and a half

Respondent: One and a half?

Interviewer: And we shall disseminate the information, am sure when we are doing that we shall call your representatives

Respondent: That is ok

Interviewer: Ok and also use the publications to disseminate the information

Respondent: Ok

Interviewer: Thank you

Participant ID	HW 004- Lira
Age	█
Date	15/Dec 2018
Venue	Female medicine ward,LRRH
Interviewer	

Today is the 15th Dec 2018 interview being conducted in the female medicine ward lira regional referral hospital, doctors' office room, and health care worker 004

Thank you very much for taking your time to participate in this interview, this is the study we are conducting to determine how to provide better health care for health workers, I mean better care for RHD patients, ah... feel free to respond in the best way possible, everything said here is confidential and there is no right or wrong answer, all answers are acceptable, Alright, tell me about yourself .thank you

Interviewer: How old are you?

Respondent: Am █ years of age

Interviewer: Ok, your qualifications?

Respondent: Am a medical clinical officer

Interviewer: Alright, where did you train from?

Respondent: From █

Interviewer: when was that?

Respondent: From █

Interviewer: Ok, so when did you qualify?

Respondent: I qualified in █

Interviewer: So, █, so how long have you been working here in Lira regional referral hospital?

Respondent: █

Interviewer: Ok majorly which patients do you usually see during your time here in lira regional hospital?

Respondent: Patients like in age group from 5-19 years

Interviewer: Ok then, could you list a few common illnesses you usually see in your patients like in most programs in a typical day

Respondent: Yes, I normally see cases like pharyngitis, laminitis, UTI's, malaria, osteomyelitis and others

Interviewer: Ok... like let's say according to age groups being the lower ones, which are the common illnesses you see in them? Like in

Respondent: Children? Children below 5 years we have pneumonia

Interviewer: Ok

Respondent: We have bronchitis

Interviewer: Yes

Respondent: We have dysentery and people with sore throats

Interviewer: Ok then of these others, let's say above 5 years, which common illness do you see in them?

Respondent: The common illness I normally see with those ones above 5 years, we see people with tonsillitis, people with laminitis, people with chronic illness like sickle cells, asthma, diabetes and many other

Interviewer: And then do you ever see people above 19 years in your practice?

Respondent: Yes

Interviewer: So, which are the common illness you see in those ones above 19 year?

Respondent: Above 19,

Interviewer: Yes

Respondent: I can majorly say as I said people majorly with chronic illness

Interviewer: Ok

Respondent: Like...we have diabetes, asthmatic patients

Interviewer: Ok

Respondent: People with recurrent tonsillitis

Interviewer: Yes

Respondent: Then UTI's

Interviewer: Ok have you ever received any training on RHD?

Respondent: No

Interviewer: Not even in school?

Respondent: In school?

Interviewer: Yes

Respondent: Yes

Interviewer: What do you remember about what you were trained in school?

Respondent: So, if I could say what I was trained in school about RHD, when we were trained on the definitions and the signs and symptoms

Interviewer: Ok

Respondent: Yes, and how to manage them

Interviewer: Ok, what do you remember?

Respondent: I remember they told me that acute rheumatic fevers is an illness caused by an auto immune response to bacterial infections with groups streptococcus

Interviewer: Ok

Respondent: Yes

Interviewer: Alright, ever since graduation, have you received any training on RHD?

Respondent: No

Interviewer: Let's say like on a typical day, how many patients do you come across with RHD during your clinic day?

Respondent: During my clinic day they can come, they can, so far they can be 3 in a day

Interviewer: 3 in a day? Ok... and these patients, do you see both the inpatients and the outpatients? Or you.....

Respondent: Outpatient department?

Interviewer: You are based in outpatient?

Respondent: Yes

Interviewer: So are you based in that

Respondent: Yes

Interviewer: Ok...outpatient...ok and then just interested in what you are being taught, what is your understanding of what causes RHD?

Respondent: According to my understanding, rheumatic fever disease according to me, it's caused by bacteria

Interviewer: Ok

Respondent: Yes

Interviewer: And then are you aware of the link between sore throat and RHD?

Respondent: Actually, not very

Interviewer: What do you mean by not very, so like do you have an idea?

Respondent: So, I have the idea that I was just with it from school

Interviewer: Ok

Respondent: Yes

Interviewer: So, what do you remember?

Respondent: So, what I can remember from what I was taught from school about sore throat with rheumatic fever is the way I understand, it is there, if someone is presented with sore throat what to do is....

Interviewer: Ok

Respondent: You need to take some investigations and you find of majorly what could have been the cause of this sore throat and you go deeper and deeper to understanding what could be the major cause of this sore throat. If you have found out what caused it, by like we have many groups of bacteria so you try to relate it to what could be the target place in the heart

Interviewer: Yes

Respondent: That is what I know

Interviewer: Ok, am going back to our previous question on understanding the causes of RHD, you talked of bacteria do you know these bacteria exactly?

Respondent: No but I can say it's in a group of streptococcal A, group A

Interviewer: Ok..., alright...ah... were you taught about what can be done to prevent RHD?

Respondent: Yes, a little bit, I was given how to treatment of rheumatic fever disease

Interviewer: What else under prevention?

Respondent: Under prevention I was also taught.....under preventionearly diagnosis and treatment

Interviewer; Ok...anything else?

Respondent: Others, I was taught about management of or prevention of rheumatic fever disease, so like I said earlier, like... early diagnosis and treatment

Interviewer: Ok

Respondent: After you have given treatment, you need to make follow up, yes

Interviewer: Alright, and then what were you taught about the treatment option for RHD?

Respondent: Treatment option?

Interviewer: Yes

Respondent: So, I can remember what I was taught with it that once you see someone with rheumatic fever disease, you can put that person on strong anti-biotic like penicillin, benzathine penicillin

Interviewer: Ok, anything else concerning treatment?

Respondent: So, things which I can add about the treatment, it's just time, its long treatment time

Interviewer: what do you understand about the long-term prognosis of RHD?

Respondent: A long term prognosis of rheumatic fever, I can say the long term is the way I understand it, long term prognosis can be what could be the cause after the treatment

Interviewer: No, the prognosis is like the outcome

Respondent: Yes. The long-term outcome of rheumatic fever disease?

Interviewer: Yes

, **Respondent:** Yes, I can say some patient or in some age group, you will find some people within that age group will start to be traumatized with what has been taking place since their understanding is still about the disease or what is affecting them

Interviewer: Yes

Respondent: Since they know about it, so they will keep on asking themselves why am i, they are doing this on me, others they are not doing this, so in the long term, they will be traumatised

Interviewer: Ok, anything else concerning that?

Respondent: That is the information

Interviewer: Ok, when do you recall the last patient, when was the last time you saw a patient with RHD?

Respondent: The last time I saw a patient with acute rheumatic fever was in sept.....was in July

Interviewer: July eh?

Respondent: Yes

Interviewer: Ok, could you tell me about, like summarise the visit like the description, the presentations

Respondent: Actually, the patient was referred from the health center within their locality where they were coming from.

Interviewer: Ok

Respondent: And he was referred to lira regional referral hospital for further management and investigation, so on arrival, the patient had a form which he was referred from a health Center where they were so on reaching on my desk, so they explained to me what was taking place until when they were given a referral form, so I did some investigations, clinical investigation

Interviewer: Ok

Respondent: and what they told me was the child had recurring tonsillitis, like it can take like 2 weeks, it comes back, two weeks, it comes back like that, so they went to a nearby facility and they were referred to the regional referral hospital and I had a clinical assessment like looking through the oral cavities and found out that there was sore throat and pain when swallowing and the patient was complaining of like she feels pain on the knee like I can say that the digits all over.

Interviewer: Ok

Respondent: And slight increase in temperature, sometimes it increases and drops drastically, it increases and drops drastically

Interviewer: Ok... other than that what else?

Respondent: so even she also told me that she has like headache which is sometimes on and off, it comes like in 2 days and it disappears, then it comes the next day like that, like that

Interviewer: Ok, so what was your management plan for them?

Respondent: the management plan for them?

Interviewer: Yes

Respondent: As per outpatient

Interviewer: Yes

Respondent: As per outpatient, after me looking at those signs and symptoms

Interviewer: Ok

Respondent: So, I had to send them to a clinic where they are supposed to be seen

Interviewer: OK

Respondent: According to the information we were given, the person presenting the complaints of the signs and symptoms of rheumatic fever disease, so there is a special clinic they normally go and attend the services for further investigation and management but from outpatient, we also put our diagnosis but we query

Interviewer: So, for you, you only suspect

Respondent: Yes

Interviewer: Ok. And then what is the average age of the patients you see with RHD, those that come to you

Respondent: According to the age groups?

Interviewer: Yes, on average, the age

Respondent: The age? It's majorly from the age, you can say from 8-12 majorly

Interviewer: From 8-12?

Respondent: Yes

Interviewer: Ok are most of them in school or...l?

Respondent: Yes, most of them, most of them are in school, some clients who come, most of them are primary pupils, and others are secondary students

Interviewer: Ok, so you don't have any who come and they are not in school?

Respondent: Others come and tell you that am no longer in school

Interviewer: Ok, so they give reasons why they are no longer in school?

Respondent: Yes

Interviewer: And what reasons do they give?

Respondent: The major reasons they normally give is the disturbance from their step mothers, they have abandoned them, others the fees problems, others the distant from home to school is quite long, so that's the problem they normally give me why they are not in school but the majorly is because of the family issues

Interviewer: But not because of the disease?

Respondent: Yes

Interviewer: Ok, when you try to ask them, are they generally aware of the link between sore throat, ARF and RHD?

Respondent: Some others when you have asked, they say they have heard of this over the radio stations and village health teams about the relationships between sore throat and ARF

Interviewer: Ok

Respondent: So, others come when they have already heard that information, we heard over the talk shows, over the radio, those ones whose parents are educated and other over the village health team

Interviewer: Ok, whenever they come to you, what sorts of symptoms do they describe to you, most of your patients?

Respondent: The symptoms, they normally tell us about what they have gone through, majorly others can say I have been having this long thing for a long time, I don't know what could be this, so I have come to the hospital to seek what could be the problem with me

Interviewer: Like do you mind listing the symptoms, what they come with or what would be presenting complains always when they come?

Respondent: So, when they come, we normally record it in our medical record forms what they are telling us about what they are experiencing

Interviewer: Ok what am trying to ask is ,can you list them, the symptoms that they always describe just like you talked of joint pains, do you know any other symptoms that they.....

Respondent: So, when they come with joint pains, they normally say that they feel like something is just scooping inside the bones, that's what they normally tell us, there is something like they are scooping my bones like roughing on a roughing, so they feel much more pain when those things are happening

Interviewer: Any other thing other than that they come and explain to you?

Respondent: Yes, others, they come like they feel like fever, when the temperature is high like they feel is associated with chills, even if during hot conditions

Interviewer: Ok

Respondent: Yes

Interviewer: Anything else

Respondent: Like others say they muscular pains

Interviewer: Ok, is that all

Respondent: That is what I can recall

Interviewer: Can recall?

Respondent: Yes

Interviewer: Ok, so generally about the follow up and adherence, is it good?

Respondent: Yes, follow up and adherence is very good for our clients

Interviewer: Do you do follow up for OPD as well?

Respondent: No

Interviewer: So how do you find out if they are really following their treatment? How they have been adhering for their medication?

Respondent: I normally come to the clinic where they do their further investigations and management and I try to check on

Interviewer: Ok, alright, so what sorts of barriers do they commonly state to getting the care that they need?

Respondent: So, what they normally tell me about the difficulties they get in their case, like one day one of them told me that whenever they come, they take a lot of time

Interviewer: Ok, what else?

Respondent: sometimes they even say like when they are moving from their villages to the healthcare point. They always delay and sometimes the mode of their coming like transport, like sometimes when they are in for their...like I say, like the day when they say you come for treatment

Interviewer: Yes

Respondent: The revisit day, so they say whenever they are coming, sometimes they don't get transport from where they are coming from and they delay

Interviewer: Other than the delay, do they also give you other barriers like the challenges they face to getting health care that they need?

Respondent: So what I can recall about the challenges, they normally get like when they are referred maybe to a...like treatment section, so when they say like this treatment, we are going to maybe give you a package and you go to the nearby health facility, when you find it difficulties to come to the referral hospital by trained health workers from the health facilities like I can say from H/C 111,H/C IV within their localities, they normally say that from there, the health worker are harsh on them sometimes

Interviewer: Ok

Respondent: They don't care about them to the expectations they want

Interviewer: ok then, that was according to them right, now this question is what barriers or what challenges do you perceive that they face in getting what they need according to you

Respondent: My challenges?

Interviewer: No, the challenges you assume or you feel the patient get in receiving health care that should...like what do you think the patients are facing? The other one was on the point of the patients, what they tell you they face but this time around, it's you, looking at it in their views, what you feel that they face, the challenges.

Respondent: The challenges they face according to me?

Interviewer; Yes

Respondent: One I can say, to me I see they come when they are already, like I can say they are traumatised

Interviewer: Ok

Respondent: Whenever you try to explain what is happening to them, they still have that mentality that this thing is like this? Why is this so different from others, so it refers me back to my first statement that they are traumatised?

Interviewer: Ok, what else do you think that they face? Other challenges that they face?

Respondent: stigma

Interviewer; Ok

Respondent: Yes

Interviewer: Ok, any other things?

Respondent: That's according to me, how whenever they come

Interviewer: Ok and then this is in terms of health system barriers, is the administration working for you and leadership in the district like do you think it's doing well?

Respondent: To me I think there is a gap

Interviewer: like?

Respondent: One is communication gap

Interviewer: Ok, do you mind explaining this

Respondent: The way I can explain my communication gap between the districts as you have stated, sometimes you find that the district does not even give the adequate information of what is taking place, they give partially

Interviewer: ok, **other** than communication gap, anything else?

Respondent: I can say yes, like teamwork

Interviewer: You feel like there is no team work

Respondent: Yes

Interviewer: Or there is team work

Respondent: You can say there is adequate team work

Interviewer: Ok then, in terms of funding for health care in generally on RHD in particular, do you think they are aware of this information?

Respondent: Can you please come again?

Interviewer: Like what do you think the district or like let's say in terms of funding for health care

Respondent: Yes

Interviewer: What do you think, ok generally and particularly RHD, what do you think is not being done well

Respondent: Like when.....

Interviewer; And the funding

Respondent: And the funding?

Interviewer: Yes

Respondent: Underfunding like I can say that there is also inadequate mentorship for ARF

Interviewer: Ok, other than that, anything else?

Respondent: That is what I can state

Interviewer: Ok and then when you look at the health workers, what you think it's not working well for them

Respondent: In what ways?

Interviewer: In terms of just like, let's say, what do you think is being done well for you and why do you think so? Like what you think should have been done which is actually not being done

Respondent: Yes

Interviewer: You as a health worker

Respondent: I can say in terms of facilitations?

Interviewer: Yes

Respondent: It is not being done well because sometime you see we have like I can say there, staffs only strictly working on those things, they don't involve others, so in the process, it brings tension between that then they will say that maybe these are the people specifically working for that like I can say ARF

Interviewer: Yes

Respondent: So that is what I can explain about that

Interviewer: Ok, what would bring about the team bit you talked about previously?

Respondent: Yes

Interviewer: Ok and why do you think it's happening like that

Respondent: The way I think it's happening like that because there is a principle which says a boss will always be a boss right, so when someone is above you and said something, there is no way you can go beyond that person

Interviewer: Ok, and that's happening here like for the different health workers.

Respondent: I can say yes

Interviewer: Has it happened in several department or we have specific.....

Respondent: So, like in my department, so it has happened because you see like when like the fellow staff like my fellow staff, they say you go to that people, you will handle that case, so it means there is a gap between there

Interviewer: Ok, so do we have like are the medicines available in the hospital?

Respondent: For ARF

Interviewer: Ok, generally

Respondent: Yes, the medicine for ARF is available

Interviewer: So, what would you say, it's not working well for you, let's say in terms of medication

Respondent: In terms of medication?

Interviewer: Let's say benzamine penicillin, heart failure drugs

Respondent: So, I think I have no problem with medication

Interviewer: Ok

Respondent: Yes

Interviewer: You think it's available

Respondent: Its available 24 hours

Interviewer: Ok, even heart failure drugs?

Respondent: Yes

Interviewer: Do you do echo cardiography in our facility?

Respondent: Yes

Interviewer: Yes, you do echo? And everyone has access to it?

Respondent: Yes

Interviewer: Ok and then how would you describe your record department?

Respondent: The record department I would say, there is still gaps in the record department

Interviewer: ok do you mind explaining that?

Respondent: Yes, the reason why I have said the record gaps like am looking in the outpatient where we like see patient referred from a health facility, we don't have registers to record those ones referred or those ones we have seen, then we have sent to the clinic for ARF

Interviewer: Ok, so we still have that record gaps

Respondent: In terms of the registers

Interviewer: Do you have like an ARF register for RHD patients in your department?

Respondent: No, I don't have in my department

Interviewer: Oh.... what of any, do you ever record or keep any information concerning those patients?

Respondent: No

Interviewer: Ok, in your department, do you like have any guidelines and protocol for RHD care

Respondent: Yes

Interviewer: Including the referral pathways:

Respondent: No

Interviewer: But you have the guidelines, right?

Respondent: Yes

Interviewer: We were looking at the barriers to the local health system but now let's look at the enablers, what do you think that the administration and leadership in the district has done well for you or for the district in general?

Respondent: Let's say they have done best in sensitising the community

Interviewer: Ok

Respondent: Yes

Interviewer: What else:

Respondent: that is what I can say

Interviewer: Ok what of in terms of funding of health care

Respondent: Funding health care?

Interviewer: Yes

Respondent: I think in the funding of the health care within, from the district

Interviewer: Yes, ok that one could go as far as government, in general ministry of health, do you think or what has been done well in terms of funding of health care and for ARD in particular?

Respondent: I think the funding is fine according to me

Interviewer: Ok, so what are you happy about in terms of its funding?

Respondent: In terms of its funding, am happy about like when there is follow up, some times when we don't do a follow-up or generally don't follow up, we normally lose our clients so with follow up and the I am...can say that majorly the transport refunds for those ones who are enrolled now is quite, I can say it's quite good

Interviewer: Ok and then what of the health workers, what do you think you are doing well, ok all the other health workers generally in terms of waiting time and the quality of care offered to patients?

Respondent: I think the health workers, we have improved

Interviewer: Ok what do you think they are doing well, like when you look at them and the services they are offering, what do you...do you think they are doing well?

Respondent: Like I can say the clinic is doing well because you see like the referral funds has been given to majorly the health facilities within and where the patients are coming from or I can say the clients

Interviewer: Yes

Respondent: Whenever they hear about this, they go to health facilities, they are given forms, they make the work easy when they come, and we do our assessment where they get the exact help from.

Interviewer: And then ok I had asked about medication previously; do you think like what do you think the hospital is doing well in terms of medications like for the clients?

Respondent: So, the hospital is doing well in terms of medications like one, we don't have like stock out of those drugs within the facility

Interviewer: Ok so at all times you have like BPG drugs, the anti-coagulation drugs and the anti-heart failure drugs available?

Respondent: Yes

Interviewer: Ok and you said they can get all these drugs from the pharmacy /hospital pharmacy?

Respondent: Yes

Interviewer: There is no time they are supposed to buy?

Respondent: I have never come across that

Interviewer: Ok and then in the records, what are they doing well, what have they done well? records department

Respondent: Records department?

Interviewer: Yes

Respondent: I think they are doing well because they are capturing the data when these clients come

Interviewer: Ok

Respondent: they are there like the time they have reported like even taking other vitals, the return date, the return date, they have been captured in the register, I can say in the register but in the outpatient is still the problem to us

Interviewer: So, concerning your perception of patient outcomes ah...do you think they get the care they need or not? Like most especially surgery

Respondent: surgery?

Interviewer: Yes

Respondent: For the case of surgery, I have never come cross

Interviewer: Ok

Respondent: Yes

Interviewer: And why do you think the? Is surgery offered in lira regional referral hospital?
Concerning RHD

Respondent: That one I have never come across

Interviewer: Ok

Respondent: Yes

Interviewer: That one you not sure?

Respondent: I am not sure

Interviewer: Ok, but aside from surgery do you think these patients are getting the care they need

Respondent: Yes

Interviewer: According to you

Respondent: According to me

Interviewer: Ok do you have any patient safety or quality of care concerns?

Respondent: To me, no

Interviewer: No! Ok like you feel the patients are safe in the hospital

Respondent: Yes

Interviewer: Not concerned about anything? , what of the quality of care, like is it really fine

Respondent: Yes, it's the quality of care they are giving them is fine

Interviewer: You don't have any doubts

Respondent: I don't have

Interviewer: Or worries about it

Respondent: I don't have any doubts or worries about it

Interviewer: Ok, during you...This time around that you have been in the hospital, are there any preventable deaths that you think you could have been actually stopped in the hospital

Respondent: Yes ,according to ARF, when we ,they are early diagnosis and put on treatment, we prevent like substance which may happen, when we like they could have been where they not minding about what is happening to them ,we put them on treatment, it means we are preventing other complications of the heart

Interviewer: Ok, ah...So now leaving a side the ARF and ARHD

Respondent: Yes

Interviewer: Have you like are there any prevented deaths that could have been occurred in the hospital that you feel shouldn't have happened? Like you look like this person wouldn't have died had this and that been done?

Respondent: No

Interviewer: No?

Respondent: Yes

Interviewer: Ok, do you think patients are dying in the community without presenting to the hospital for care?

Respondent: Yes

Interviewer: What do think is causing that?

Respondent: In the community?

Interviewer: Yes

Respondent: Like I can say knowledge gap

Interviewer: like could you mind explaining further?

Respondent: I can say knowledge gap in terms of like we have like few staffs who can explain and may be sensitise the community about, maybe what is happening ,currently happening

Interviewer: Ok

Respondent: Yes

Interviewer: Alright..., now for these patients who die in the community before they even reach in the hospital, what do you think causes that?

Respondent: Sometimes the cause of those things is like when we have like culture and religion

Interviewer: Yes

Respondent: So, you find where religion is saying ah...this is manageable by prayers, so it's not treated to medical, others you find this culture is saying with this complaints like this kind of infections

Interviewer: Yes

Respondent: We use like local herbs, so they don't dwell with modern techniques, like I can say with the lines of medicines, **So** there are cultures which they do away with those things

Interviewer: Ok, in your option, what do you think are the...ok in your opinion on ...,that do you think are the most important things that ministry of health could do to improve on outcomes of this place?

Respondent: More training of staffs and village health teams to sensitise the community

Interviewer: Ok, what else?

Respondent: I have said about training of staffs and more VHT's and putting monitoring and evaluation teams

Interviewer: Where do you think that could be placed?

Respondent: like I can say in the referral hospital,

Interviewer: Thank you so much, aside from that, do you have anything you have to say?

Respondent: like?

Interviewer: To add on

Respondent: which area specifically?

Interviewer: Anything, anything concerning what we have learnt, and what we have said today

Respondent: No

Interviewer: No! Ok thank you for taking Part in this interview, yeah, thank you, we shall get back to you

Participant ID	HW 005 - Lira
Age	■
Date	16/Dec/2018
Venue	Nurses Office, LRRH
Interviewer	

Thank you, madam, for allowing to be part of this interview, let me just know but before we begin, just remember that there is no right or wrong answer, we just want your opinion.

Respondent: Its ok...you are also correct.

Interviewer: Yes, not even correct because what you tell me is what I will write.

Respondent: Like ourselves, I wanted to learn.

Interviewer: You wanted to learn?

Respondent: Yes, so that when you are interviewing, I will know how much I know

Interviewer: And then we ask you to be honest as possible and share your opinions, we shall not link your identity whatsoever and your comments to the reports we produce, so now for record purpose, this is the 16th of December 2018 and we are sitting at the nurse's office at lira regional referral hospital. Ok just tell me a little about yourself

Interviewer: How old are you?

Respondent: I am ■

Interviewer: What are your qualifications?

Respondent: Nursing ■

Interviewer: Where did you train from?

Respondent: ■

Interviewer: When was that?

Respondent: ■, that's when I completed

Interviewer: For how long have you been working here at lira regional referral hospital?

Respondent: I have been working for ■

Interviewer: Ever since you came around, when you look around at the demographics, what are the common ages you see of the patients?

Respondent Because I'm working at emergency, I always see the young.

Interviewer: Between what ages?

Respondent: I have always seen between the young around 15-20 years here.

Interviewer: Which are the common illness that you treated?

Respondent: At emergencies?

Interviewer: Yes

Respondent: Apart from RHD?

Interviewer: Yes, apart from RHD...

Respondent: We are having those one which come with like sinuses, then malaria, T.B

Interviewer: Among children, which are the common one?

Respondent: Among children, we have malaria mostly, sickle cells, they come in as a crisis

Interviewer: Ok...have you encountered the RHD patients?

Respondent: Yes

Interviewer: Ok you see them, then the RHD, those who comes with the complication with RHD, like on average in a day, how many have you seen or in a month?

Respondent: I see like 5

Interviewer: And then, have you got any special training on RHD?

Respondent: No

Interviewer: During school days?

Respondent: No, they just taught us in school, they taught us as atopic

Interviewer: So, they taught you something?

Respondent: Yes, they taught us something

Interviewer: Ok and after, have you had any training on RHD?

Respondent: No

Interviewer: No and then, what do you remember about it, which area were they tackling when they were teaching you?

Respondent: They were tackling about the causes, the bacteria that causes it and how it comes about and because I remember they said it's a complication mostly a patient who first develop a sore throat, then it becomes a complication

Interviewer: As a complication?

Respondent: Yes

Interviewer: Ok, did they mention about the management?

Respondent: Yes, they mentioned about it.

Interviewer: Yes, what do you remember?

Respondent: Like they told us like in case someone has developed sore throat, then you have to manage it early enough with antibiotics, then maybe when it comes in with complication of that kind, then they put that patient into nursing

Interviewer: Ok weekly or monthly

Respondent: Monthly

Interviewer: Ok thank you. Have you attended any CME on RHD?

Respondent: Yes, I have only attended once when I had just come here

Interviewer: Since you came here?

Respondent: Yes, so they are teaching us

Interviewer: So, they are teaching you? How many, so far have you attended?

Respondent: Just because I am always busy this side, I always miss

Interviewer: So, you have only attended only once?

Respondent: Only once

Interviewer: Once eh

Respondent: But I am always seeing on the notice board eh..., they always call people for the training on CME'S

Interviewer: CME'S

Respondent: But you find when you are a tutor and you can't leave and go and attend and being an emergency unit

Interviewer: So, there are times when you are alone

Respondent: Not a times am always alone, there are only four of us and they put one on duty.

Interviewer: So, you work from what time up to what time when on your duty?

Respondent: when it's your duty, you work from 8:00 -2:00

Interviewer: To 2:00

Respondent: Yes, then evening from 2:00 – 8:00

Interviewer: You have four shifts?

Respondent: Three shift, for night you come in and leave at 8; 00 in the morning, like now I am leaving

Interviewer: So now like typically on a normal day, like how many cases can you get during your shift, how many emergency cases?

Respondent: like 10.

Interviewer: Since you said like in a month, you see like 5 RHD patients, when you look at those patients, are they usually inpatients, do they end up being inpatients?

Respondent: Yes, mostly like those who come when they are already badly off, so we admit them, then those who are not badly off, they go to OPD

Interviewer: They go to OPD?

Respondent: And we don't capture those ones

Interviewer: Ok those ones you don't get to see?

Respondent: Yes

Interviewer: Ok, so you told me about your little understanding of RHD?

Respondent: Yes

Interviewer: So, you said it's a result of untreated sore throat

Respondent: Yes

Interviewer: So just to get more details, how does it come up according to you?

Respondent: The bacteria itself?

Interviewer: The sore throat

Respondent: I have forgotten it

Interviewer: So, what happens if anyone has that?

Respondent: What I know, it walks within the blood stream and as it ends up reaching the heart, it spoils the blood valves

Interviewer: That's what you know?

Respondent: Yes

Interviewer: So then, are you aware of the link between sore throat and RHD? Do you know the association?

Respondent: I am not certain

Interviewer: Are they related in anyway? Sore throat, getting sore throat and RHD?

Respondent: The relationship I know is that the causes are the same, the bacteria which causes it when it has been more or when it reaches the blood stream, it spoils the valves that is what I know.

Interviewer: Ok, what were you told can be done to treat RHD, what did they teach you at school?

Respondent: Early treatment of or when someone develops the sore throat, you have to treat it early enough before the bacteria moves to other parts of the body like the heart.

Interviewer: So, what were you told were the treatment options for RHD? What are the different treatment option of RHD you were taught?

Respondent: What I know and what were taught and what I am always seeing because like this people are always treating them from our place there, these people, the vevida, they always give vaccine protection

Interviewer: then the other treatment option?

Respondent: I am not sure off

Interviewer: You are not sure off?

Respondent: Yes

Interviewer: And then, what are your understanding about the long-term prognosis of RHD?

Respondent: The prognosis

Interviewer: Yes

Respondent: What I always see, it's not always good, it's poor

Interviewer: It's poor?

Respondent: Mostly patients come in when they are not heathy, maybe for those ones who always pass this side of the tent but these ones who always come in, they are really sick and they don't know about this program, it is always poor

Interviewer: It's always poor?

Respondent: Yes, because we always lost them

Interviewer: You have lost them!

Respondent: Yes

Interviewer: And then, so tell me about your encounter with patients with RHD eh....do you recall the last patient you saw who had RHD, when was that?

Respondent: Recording them?

Interviewer: Do you remember you last saw a patient with RHD, how did they go?

Respondent: Remembering the time I encountered that patient...

Interviewer: The last patient.

Respondent: Yes, it was last month.

Interviewer: Last month

Respondent: Yes

Interviewer: So briefly tell me how it was with that patient.

Respondent: Yes, given on that and she was brought here at night, when she was anaemic and she had become oedematous all over the whole body and the face was puffy and she was anaemic at that time, so we had to rush for blood transfusion

Interviewer; Yes, but did you know straight away that she had oedemic injury?

Respondent: Because she had never come here

Interviewer: Ok and you straight away admitted her?

Respondent: Yes, I worked on her on that night, then the following day she was brought here because we don't always take long with them at the emergency, we always give them the first treatment, when they stabilise abit, we transfer them to the various wards according to their conditions and because when she was brought here, I didn't follow her.

Interviewer: When you look at your RHD patients, what is the average age you see for RHD patients?

Respondent: The average age, like that girl was 14, hmm..., was 14 and another one was 15, around 15 hmm... Another one was 20years old

Interviewer: Another one?

Respondent: But that one passed on, that one of passed away from here,

Interviewer: That one of 20 years?

Respondent: But those two I didn't I didn't follow up after they had been transferred here

Interviewer: So, the ages you see is between 14-20?

Respondent: Yes

Interviewer: And then if you follow, were they in school or out?

Respondent: They were in school

Interviewer: And then, any children you saw between the ages of 5-10 years that are sick?

Respondent: No, I didn't see

Interviewer: You didn't see any young children?

Respondent: Yes

Interviewer: When you see these patients are they generally aware of the link between sore throat and Acute Rheumatic Fevers and RHD?

Respondent: No, they are not aware

Interviewer: They are not? And what symptoms do they describe to you when they come?

Respondent: The symptoms they always talk

Interviewer: Present with or they

Respondent: They always talk of pain of the heart, then the chest, they talk of the pain always

Interviewer: So, it's always the chest pain?

Respondent: Ok, they always come and complain of the sore throat, they always come with complications

Interviewer: And then are they good about follow up and that of treatment? When you look at those issues

Respondent: Yes, for those ones that come here because for us we always link them when we get patients with RHD, I mean, patients of that kind, I think they always link them up with those people, this project. so when they are coming back, they always come back together but they always come back to us

Interviewer: Yes...but do you see that they adhere to the treatment?

Respondent: Yes, but others do not

Interviewer: They don't, what could be the reason?

Respondent: For what I know, they have it in mind that it's incurable, it's the things that makes them not to come back, that's it's a wastage of time

Interviewer: What else do you think always makes them not to come back?

Respondent: Other maybe coming from far deep in the village and they may be lacking transport

Interviewer: Transport?

Respondent: To bring them

Interviewer: Any other reasons, those are two, any other reasons?

Respondent: Maybe fearing injections because others complain of the injection being so painful

Interviewer: Being so painful.

Respondent: Because there is one of recent, there is a daughter of one of the staff here, she is at campus, Lira University, she told me she used to have a sore throat but they used to take it as a mere cough and not sore throat. Then of recent it's when they discovered that the heart has got some complications, they brought her here so of recent she was telling me that she was given the medicine and they have told her that she should be injected for some good times until she makes 25 years and she said it's so painful and I am going to start dodging. I think it's the painful injection that makes them not to come

Interviewer: Ok any other reasons maybe they have shared with you?

Respondent: No, I only had a conversation about it with her, those others have never had the conversation.

Interviewer: You have not had any other conversation, then if you look at those who come, why do you think they come. What motivates them to come?

Respondent: Just because they have seen there is some improvement and maybe they have been convinced enough that there is hope of getting cured

Interviewer: Who do you think could be convincing them?

Respondent: Mostly its people who are doing it, these people of the RHD because we are also utilizing them because once we get clients who are not aware of it, we always connect them to them at once, and they are always there for them.

Interviewer: Hope of getting cured!

Respondent: When they are getting better

Interviewer: What else because we need to learn, we need to know what motivates them, what other reasons?

Respondent: Other reasons maybe, I think this people, they are always telling them that they are there for them and now they know that there is treatment for it not like those days and if they come, they find when there are no drugs but now days the drugs are there

Interviewer: So, the drugs are now available?

Respondent: The ones that I always see them are being injected like I told you that they are always treated from our place here at emergencies,

Interviewer: So basically, the project has brought in the medicine which was not there before?

Respondent: Yes, you know for government, drugs always be there but when they are not enough, they might come in when they are there but like they may come in for the review when the drugs are there then next time they tell them to come back for the review, they find when the drugs are out of stock, so that one demotivates them from coming back, but this time around whenever they come, they find the drugs there

Interviewer: Ok...thank you for those points, so that is the reasons you think some of them are coming, any other reasons?

Respondent: None

Interviewer: None

Respondent: Yes

Interviewer: Ok...Thank you for that, you as a health worker are there any barriers you face when treating the RHD patient

Respondent: The barriers we face

Interviewer: The problems or the difficulties

Respondent: like when they come in when they are really sick before they get to this side of the project, the barriers is because when we don't have this other drugs, For them apart from the delay, sometimes they come when they have heart failure, the drugs I always write for them to buy and you know buying, they may have come from the village and the only have transport for bringing them here, mostly those drugs, they don't be with them and you find when they are missing their drugs and they are not taking the rightful treatment like expected per years

Interviewer: What other barriers are you facing?

Respondent: Maybe also the beds

Interviewer: The beds?

Respondent: The beds, to position them when they come with that extent of heart failure, you find that they don't have enough beds, more especially when you find that the patient is already there, hmm, like for us, we have like one cardiac bed, so you find that inpatients like I told you that one those ones with cystic River Cirrhosis (CRC). You find when the beds are not enough it becomes a challenge to us who are nursing them

Interviewer: How do you always improvise in such a situation?

Respondent: We always improvise, we always tell them to put like if they have come with clothes, they make those clothes like a pillow to raise it up but not always enough

Interviewer: Okay other challenge you are getting?

Respondent: No

Interviewer: Let's talk about the training you have in RHD management, how is it, how do you look at it, do you feel like it's adequate

Respondent: Yes, it is, its adequate like I told you, I always don't find time for the CME'S like I always don't find time for it, am even busy, I reached when they have already reached the middle part of it, I didn't attend it fully but I always miss it out because am busy

Interviewer: But do you always feel comfortable treating an RHD patient when you feel lack some knowledge about it?

Respondent: Yes, I do feel that because I lack some management knowledge

Interviewer: So which area would you want to be trained on RHD treatment?

Respondent: How to nurse them, also the management, however much the doctors are there to write the medicine, still they might come in when there are no doctor and also how to prevent it so that you can also sensitise the people.

Interviewer: Ok... and then when you look at the administration, let's start at the district, the leadership at the district, do you work, how is it? Is it working to treat the patient?

Respondent: They do but not that much,

Interviewer: What is lacking?

Respondent: Like we are understaffed like I told you before, you find that you leave the duty when you are so tired, we tried to complain about it to the administration but no action has been taken yet.

Interviewer: So, you tried to talk to the administration, what did they say?

Respondent: They promised like when the volunteers come in, we shall sign in the volunteers, but you know if someone is not earning, you can't work well.

Interviewer: Motivation

Respondent: Still it comes back to us, like now I have just left now and yet I was supposed to leave at 8:00 because there was a volunteer who was supposed to come in but she came in at her own time and you know of course you can't be on her neck that you come early because you know tomorrow she might not come back

Interviewer: Those are some of the challenges that you have?

Respondent: Yes

Interviewer: And when you look at..... so in case you need things to use to treat the patients ah.... and you approach the administration, what happens? How is everything?

Respondent: For any patient?

Interviewer: Yes, the things you need to do your work

Respondent: Like when we need which things

Interviewer: Like maybe things like the sundries

Respondent: They always provide when they are there, yeah, like of recent ,I think I just saw the vehicle coming in ,I think they have brought the drugs but we have not been having drugs

Interviewer: Like drugs for which diseases?

Respondent: Like for all the emergencies that comes in

Interviewer: You didn't have drugs?

Respondent: Yes, like the ceftriaxone, like these other drugs, we didn't have them

Interviewer: And for how long has that been?

Respondent: It's now like two weeks

Interviewer: Two weeks!

Respondent: Yes

Interviewer: Ok, like in such an incidence where the drugs are not available, how does the administration handle the situation? So how do you survive?

Respondent: Anyway, for that case I think it's always the in charge who goes to the administration but what I know, we always go the pharmacy and if the pharmacy is not having the drugs, they tell you that they are not there, we shall take that

Interviewer: So, what do you do to the patients?

Respondent: When they come in, we always write for them to go and buy what the doctors have written eh...

Interviewer: Those who can't afford, how do they survive?

Respondent: But they always struggle, laughs.....

Interviewer: They always struggle and buy?

Respondent: But sometimes like at night , there are times when they come at night and there is no where you can send them to go and buy and you really see these patients needs the drugs and we always look from the different wards to see which wards have and they always help

Interviewer: They always help?

Respondent: Yes

Interviewer: Have you ever encountered a situation where you failed to get the drugs?

Respondent: Yes

Interviewer: And the patients could not afford?

Respondent: Yes

Interviewer: How do you...

Respondent: Like I told you at night when the pharmacies are locked, we always just keep the patients there until morning

Interviewer: Until morning?

Respondent: Yes

Interviewer: Pharmacies only work during day?

Respondent: Yes, pharmacies I'm talking of is the outside one

Interviewer: The outside one? But yours only work in

Respondent: During the day and we always collect drugs in the day time

Interviewer: When you look at the waiting time, the time the patients waits before they are worked on, what do you have to comment on this? How is it?

Respondent: But in emergencies, what I was saying they trained the staffs though I was not there, that time they trained them on how to handle the emergencies, they don't stay for long to be treated even when the doctors are not available, at least the nurses try their best to treat them

Interviewer: They try their best and then, what happens to the other wards? How are the wards there?

Respondent: There am not certain because ever since I came here, I have been on the emergency.

Interviewer: You have only been at the emergency?

Respondent: Yes

Interviewer: Ok and then...

Respondent: Because at emergency, we always work on them very fast

Interviewer: In your department at emergency, are there a times when you don't really have the doctors around

Respondent: Yes, there are times when we don't have doctors

Interviewer: Typically, what time?

Respondent: Mostly when these intern doctors are leaving because we have only few doctors, you find when those ones are also committed in those other wards, the interns are the ones who mostly help us.

Interviewer: So, when they are not around, how do you handle it when they are done?

Respondent: Because we always wait for the doctor to come around

Interviewer: And do you get doctors at night?

Respondent: At night?

Interviewer: Yes

Respondents: The interns are always there, they are allocated for night duty

Interviewer: So, what you are trying to say is that you only have two doctors for the wards, two who are not doctors, only two are specialist?

Respondent: I am not sure of the number they are few that's what I know

Interviewer: So, when you can't access the interns, when you can't access the doctors, who manages the patients for those who would have needed the attention of the doctor?

Respondent: We always call

Interviewer: You call, and then, do they respond to the call

Respondent: They respond.

Interviewer: Ok, when you look at the quality of the care the patients get, how is it?

Respondent: The?

Interviewer: Quality of care the patients get

Respondent: It's always good

Interviewer: Are you satisfied with it or you find when there is something lacking?

Respondent: Yes, I am

Interviewer: Any room for improvement, any areas where you feel they should improve on or assist you to improve where they are treating the patients?

Respondent: The areas they should improve on like I told you understaffing, at least they should increase on the number of staffs because this also effects on the performance if at all we are not there and you find they need quick attention, we find that working on them at ago when you are alone is hard

Interviewer: So, have you seen/experienced any death which could have been prevented?

Respondent: You know there are a times when you see what happened could have not occurred but simply because of some or maybe something that didn't work out well caused it to occur.... that we call those prevented ones that Surely wouldn't have been the case to occur,

Interviewer: But maybe because of some reasons?

Respondent: I have not witnessed

Interviewer: You have not ehh...and then you talked about medication and you said that sometimes you don't have the heart failure drugs, how about BPG drugs and then anti-coagulation drugs? Do you get them, do you have it?

Respondent: I remember those days there is a time I found when I had just come, in our 'ka' store, I found some heparin, these days I have never seen it.

Interviewer: You never saw it? And how much is a doze for those guys when they send them outside, how much, typically, on average, how much do they pay?

Respondent: A doze

Interviewer: Yes

Respondent: Ah..., that one I am not sure

Interviewer: You are not sure?

Respondent: Because we don't always send them but

Interviewer: You don't know how much they spend?

Respondent: Yes

Interviewer: And then, when you look at the diagnostic, how are the stock? Are you happy with them, are they working for you, like if you got a patient with RHD and they need to do maybe echo-cardiography, can they access those services?

Respondent: Yes, they do

Interviewer: Do you have the access?

Respondent: Yes, we don't but we utilize these people

Interviewer: You use the

Respondent: We always send them to the tent

Interviewer: To the tent but are the hospital safe?

Respondent: It is

Interviewer: And then let's look at

Respondent: I'm not sure about the hospital but always I send them there

Interviewer: You send them there

Respondent: Yes

Interviewer: When you look at the health information system and medical record system, what do you have to say? Is it working for you people?

Respondent: Yes, it's working

Interviewer: It's working?

Respondent: Yes

Interviewer: Any gaps that needs to be improved?

Respondent: Yes

Interviewer: Like just in case you want to access some file of a patient who came in maybe a year ago, is it easy to get that file for treatment?

Respondent: Like for us here, we have our register where we enter all the patients we receive, just that we don't always specify like maybe let this be for this group of people that is the only gap I see.

Interviewer: Ok and then how do you look at the integration between facilities, let's look at, first let's talk about the in patients, out patients and the register, how do you look at them? Do you have the register for RHD patients?

Respondent: Here for emergency, we don't have

Interviewer: You don't have?

Respondent: Yes

Interviewer: And then is there an integration and linkages between facilities, like in the hospital, do you have a teaching hospital

Respondent: No, it's a university hospital

Interviewer: A university hospital? You don't have a university hospital for lira?

Respondent: just heard that they are trying to open it

Interviewer: Ok, other facilities, is there any linkages between these hospitals here and then those health centres are there

Respondent: On RHD or on all conditions?

Interviewer: For all conditions

Respondent: There is because they always send in their patients

Interviewer: They send their patients? And the information flows well between the facilities?

Respondent: Yes

Interviewer: Like you get a referrals, do you have the details on the referral letters and then how about RHD'S specifically, is there any integration linkage between the two

Respondent: I am not sure

Interviewer: You are not sure about that and how about registers for acute rheumatic fever, do you have them here?

Respondent: Like I told you in our emergency, we don't have them

Interviewer: Do other departments have them:

Respondent: I am not sure about the other department

Interviewer: Let's look at the guidelines and protocols for RHD, care you have them here?

Respondent: We don't

Interviewer: Or could you be knowing how referrals are made for RHD patient

Respondents: No, I don't

Interviewer: You don't? Do you think it's important to have the guidelines and protocols?

Respondent: Yes, it is

Interviewer: How would you utilize it?

Respondent: At least they guide you on how to take care of the patients and also how, like where to send them

Interviewer: Ok and then, so you said when they come to the emergencies, how do you refer them for care after emergency or could you be knowing where they refer them too

Respondent: Yes, what I have always seen doctors that they do, they always call these people, when these patients have been brought, they always call them to come in at least I have always seen her come for them.

Interviewer: Let's look at the health system enablers, ah...so looking at the administration, is that working for you

Respondent: The?

Interviewer: The administration

Respondent: What?

Interviewer: Is it helping you to do your work well, has it enabled you to do your work well?

Respondent: Yes

Interviewer: Any gaps where they need to improve?

Respondent: Like I told you, improving on staffing

Interviewer: Improving on staffing ehh..., when you look at funding how about that in general to the health services and health care?

Respondent: The funding

Interviewer: Is it working for you?

Respondent: With funds I don't know

Interviewer: Are you getting enough funds to do your work to treat the patients better?

Respondent: The funds what I know is the salary I get

Interviewer: Are you happy with it?

Respondent: No, I am not all that happy with it

Interviewer: Ok, looking at the funding for RHD patients, are you happy with it? Is it working for you?

Respondent: I don't know

Interviewer: You don't know, and then when you look at administration, funding health care workers, medicine and health information and medical record system and their guidelines, what have worked for you here? What do you think is working well among those things I have mentioned; administration, leadership at the district, funding, health care workers, the numbers?

Respondent: for all conditions?

Interviewer: Yes

Respondent: What I can give maybe tell about the experience I tell was in august, there was a patient who was brought in and was just transferred from Amolatar, he was bleeding, he had all the signs of ebola and that time, I was the one on duty, so we hear one of the leader was informed when they were setting off from those ends and then he directed them not to come here. They needed to be taken oba to which hospital hmm...there is a hospital where they always take them to

Interviewer: Yes

Respondent: And this patient insisted on coming here when I was on duty

Interviewer: On duty? Laughs.....,

Respondent: When they brought them here, me myself I was called by the in charge where I was that I go and see the patient but I told him that emergencies are always handled very fast laughs....so I ran there and she told me she was bleeding and that time, that was when the ministry of health was talking about the ebola

Interviewer: Ebola.....!

Respondent: So, I ran in and double gloved but I didn't touch the patient, when the in charge followed, she told me she was standing at the door way, for me I was inside, Laughs

Interviewer: laughs.....

Respondent: You screen! You screen!

Interviewer: She was ordering you?

Respondent: No, she was not, that time, you screen that patient

Interviewer: Oh my God!

Respondent: For me I don't have a patient

Interviewer: Oh my God!

Respondent: Inside of the eyelid was out, eyeballs were out bleeding, the nose bleeding, blood was coming out of the ears

Interviewer: You suspected?

Respondent: Then I suspected, I would not touch him even if I had double gloved, then I came out of that room, so I was like this man is going to die without us doing any interventions, I wanted to access him but still I was worried to touch him, then they informed the people of administration, yes it happened, by the way we didn't expect but not all that like I expected because us, though we didn't touch the patient but at least we were in close contact with the patient, they called the district, those ones didn't even act to come in very fast, that is it the deceased or the survivor's photo fast services came in late and for us ourselves decided to stay back and not go home but they were telling us that evening because the body even stayed, the man passed on, they were telling us to just call home and they bring us clothes, we bathe with JIK and then go back home, it's us ourselves who insisted and stayed that night and then in the morning, they still insisted that we go back home. Before they confirmed it, they came for it, it is, even the in charge who called the ministry, they sent that person, the driver or the driver I don't know who came and picked the sample. They came at around 10:00 p.m. being it was a Saturday, it happened on Friday then the sample was taken on that very Friday late at around 10:00 p.m. but reached that side very late, now they were telling us we have to inform their people to stay back and they are supposed to work on the things, we got the result at around 10:00 on Saturday the following day because it happened on Friday, but the world service people didn't act, they didn't help us because they were saying the ministry of health has said, just to go back home even getting the results so it's us ourselves who decided to stay here

Interviewer: That was bad!

Respondent: So, there we were like in case any other disease of any kind, we should not always act, and we should always also be taking off because the administration and the district people don't always mind about the health of their health workers

Interviewer: So, what has motivated you to continue working with these patients who come around?

Respondent: What has motivated me? Just because I was recruited and I am getting my salary, that is one because for me, I came, like I didn't tell you, I came here in January, I was posted here, I came from Mbale, I am just renting and houses, accommodation here is not enough but there is a time, there is some staffs who were transferred, they advertised the houses that were left, we applied but they took since April up to now

Interviewer: Up to now?

Respondent: But the houses are still there, only one thing that made me get angry, it was in which month, it's like am in emergency unit, that time I worked night and I worked six nights, it was almost coming to the end of the month, and this land lord of mine came and told me to leave and it was only remaining three days to the

Interviewer: Getting off the.....!

Respondent: He was requesting that he wanted to renovate his house, you have to move and get another place, so I came here because it was now hard for me that time, I was on night duty, I didn't have time and you know with emergency you leave when you are so tired. I didn't have time to move looking for another house, I came and told the person who is

responsible, I first went to the ‘‘highest bin’’, that time she was still new, I told her about the things at least they helped me to give me one of the houses as if the houses are just there empty, I put my things for a short time as I look for where to go.

Interviewer: They don’t allow you to occupy them before ministry of health?

Respondent: The ministry of health is a committee

Interviewer: You can’t be there before the committee sits?

Respondent: That’s what I was told but there is a person who keeps the things. I see that is hard for me, I failed to get where to go, I just bring the things and I keep my things with him as I look for where to get a house, that is also the challenges faced at time, I was now wondering where to go

Interviewer: Generally, do you think the patients are getting the care they need here?

Respondent: They do get, they do get the care

Interviewer: How about the RHD patients in particular?

Respondent: They also get but not so much, I remember there is a boy whom they brought here but he was referred to Mulago heart institute

Interviewer: Why?

Respondent: Meaning that we don’t have the adequate care

Interviewer: Can they access a surgery here? The RHD?

Respondent: No...

Interviewer: Why?

Respondent: Maybe because we don’t have the specialists

Interviewer: You don’t have the specialist? If you look at the patient’s safety, is it there? Any concern you have under quality care they give them

Respondent: The safety?

Interviewer: Patient’s safety!

Respondent: I have not understood the question

Interviewer: Patient’s safety, when you look at the patient’s safety and the quality of care they get, are they safe, are they getting the quality of care that they should be getting

Respondent: Yes, they do get but what I hear, we don’t have enough medical doctors that is it

Interviewer: Do you feel like generally they are worked on time?

Respondent: Yes, because always when you call a doctor who is responsible for what he is supposed to do, like if the patient has cleaned up, they always rush in very fast when you call them

Interviewer: Do you feel like they are being given adequate time to ask questions?

Respondent: Yes, they are!

Interviewer: They are given?

Respondent: Yes

Interviewer: And do you think the health workers are giving them enough information about their illness?

Respondent: They do but not all because of the overwhelming work

Interviewer: So some of the health workers are overwhelmed with work?

Respondent: Yes, because of the understaffing

Interviewer: Do you think there are some RHD patients who are dying in the communities without coming to the hospital?

Respondent: I think

Interviewer: Why?

Respondent: They are not sensitised, that's what I know

Interviewer: They are not aware of the disease?

Respondent: And others also I think they take it like be-witching, someone sees maybe a child is swelling, they take it like maybe he has been poisoned

Interviewer: In your opinion, what are the two most important things ministry of health could do to improve patient's outcome?

Respondent: Maybe they should also come up with trainings to train health workers and also down in the village, they can also sensitize the population about the diseases

Interviewer: Any other thing that they can do, ministry of health?

Respondent: They should always provide the drugs

Interviewer: Which is enough for them? Anything else before we come to the end?

Respondent: No

Interviewer: Ok, thank you for your time and the ideas that you have given to us, we surely are going to use it to improve RHD prevention and management in our country, thank you very much

Respondent: Thank you too for coming

Interviewer: Which health center are you working in?

Respondent: I am working in Alik health center II

Interviewer: Ok and how long have you been working there?

Respondent: Since [REDACTED]

Interviewer: [REDACTED]?

Respondent: Yes

Interviewer: And if you look at the demographics of your patients in your centre, which are the..., if you look at the ages that you see, which department are you working in now?

Respondent: First of all, am the in charge of that unit, so you know I come to almost across to all department

Interviewer: You cut across?

Respondent: Yes

Interviewer: So when you look at the demographics of your patients, which age groups do you see mainly?

Respondent: Between 4 years to 30 years

Interviewer: To 30 years?

Respondent: Yes

Interviewer: Do you mainly see adults or children?

Respondent: Yes

Interviewer: And then are they women or men

Respondent: Women are the majority group but with children below 4 years, male children again are the majority

Interviewer: Male children?

Respondent: Yes

Interviewer: Wow! What do you think explains that?

Respondent: With children, I can't explain well but when you look at the number of male children that come to seek the health center, they are quite more than the female children, I always try to think that maybe males are weak some how

Interviewer: And then when it comes to adults, you said it's mainly women, why?

Respondent: It's the contrary laughs...., females are three times more than the males that come to the hospital

Interviewer: Why?

Respondent: So to me I think males have a poor health seeking behavior because even in the village, people who die most are the males, secondly, they always come to the hospital when the condition has worsened, when the man is not feeling really bad, this man does not really come but women, they have really good health seeking behavior, they fear sicknesses, when a woman feels anything to the extent that even some of them come to me when they are feeling ovulation laughs...,the monthly usual pains, somebody will come. You see musawo, I feel pain by my side, then when you like try to access, you will find this woman not sick because you go back and dig past history, she will say even last months it pained me, then you just know, sometimes you just have to counsel and assure but I don't blame them, am happy with such kind of a person

Interviewer: Wow! And then what are the common illnesses that are treated at your health centers?

Respondent: The most common ones used to be malaria but now days with the issues of IRS, malaria has reduced although it has started shooting abit ehh...but not much but now the most common ones are the respiratory tract disease infections,yes,many of them come feeling cough, pain in the throat, chest pains, those things

Interviewer: So the sore throat cases, are they diagnosed?

Respondent: Sorry?

Interviewer: Sore throat cases, how are they, what are the burdens?

Respondent: Yes they are there, they always come with the issue of sore throat hmm

Interviewer: Ok, how about RHD, do you get some here?

Respondent: Acute rheumatic fevers?

Interviewer: RHD

Respondent: RHD, yes, I have seen, I have been referring people here and a good number of them were found positive

Interviewer: If you remember in the last one year, have you received any?

Respondent: Except I have not kept the records but they can reach even more than 10

Interviewer: And you refer them?

Respondent: Yes and I used to get the feedback and always when am referring them, I also tell them, please after there, you can also come back to me although some of them do not go but whether they go or not, the people who work there in the institute always when they visit, sometimes we always interact on phones, they tell me but for me always when am referring, I first call ahead to like avoid bouncing, I always don't like my clients to bounce.

Interviewer: Ok, that is nice to hear, that means there is a way you communicate to these people

Respondent: Yes I do

Interviewer: Wow! Has it helped in the....., do you see the advantage in that when you make the follow up calls?

Respondent: Yes, I have found it really very important because out of the client I do send, they have helped me find out the other diseases like for instance there was a child I sent, I was very happy with that child, the...., he was...., the acute rheumatic fever was negative but they found the child had sickle cell disease and up to now am managing the child, the child has improved compared to the way he came to me

Interviewer: Wow! Let's talk about your training on RHD, have you ever received any training on RHD during school days?

Respondent: During school days:

Interviewer: Yes, have they ever introduced a topic about RHD?

Respondent: In school?

Interviewer: Yes

Respondent: No,

Interviewer: They didn't:

Respondent: No

Interviewer: How did you get the information that you know?

Respondent: I got the information through these people who are working in the acute rheumatic fever, I was called for a short training in lira hotel, then they briefed us, by the way I was working and I think I used to like make them pass a lot of them minus me realizing their conditions because you find someone every time having cough, we could but not having that in mind, after interacting with these people, I went back with the forms, started now accessing them, somebody comes, there is fever, joint pains, cough, what....that has not been treated, whether treated but with no improvement, so such are the cases I have been sending here

Interviewer: So before you got that message, what would you do with those patients who had those symptoms?

Respondent: what I would do with those patients, I used to treat them first at contact, when they come back again with no improvement, I would find them referrals and refer them

Interviewer; To where?

Respondent; To the exact place, the way I do it now days, those days I could just say, you go to lira regional hospital but you know, when they come, they go to OPD and even those days lira used to miss, the regional referral used to miss because they used to come to OPD and then the doctors may see the treatment I have given and also change to stronger anti biotic,.

Interviewer: Ok, so that is how it is?

Respondent: Yes

Interviewer: And then after graduation, these people of RHD who trained you about RHD?

Respondent: pardon

Interviewer: Since you graduated, is the project here?

Respondent: Yes

Interviewer: Who trained you?

Respondent: Sorry?

Interviewer: Have you had any CMEs on RHD management or prevention?

Respondent: From my unit?

Interviewer: Yes

Respondent: Yes, I always have CMEs with my staffs

Interviewer: But have you ever introduced a topic on RHD?

Respondent: Yes, now days even if am not in the facility, any staff give health education to the OPD about that

Interviewer: Have they all been trained?

Respondent: No, they have not all been trained but I have been hinting the information through CME

Interviewer: Ok, wonderful, now before you came to these guys, you didn't have this kind of CMEs?

Respondent: No

Interviewer: Ok thank you, so you made a record at all times?

Respondent: Yes

Interviewer: In what times

Respondent: sorry?

Interviewer: In what period?

Respondent: Sometimes even in a day, I could transfer ,it depends on how they come like in a week, I could send 3-4 like that ,ok you said that you have asked only for the last one year but in total, those that I have sent here are more than 30 even

Interviewer: They are more than 30?

Respondent: Actually I interacted with her at one point and she told me that I am the one who has been sending the highest number

Interviewer: The highest number?

Respondent: I got even the motivation laughs....

Interviewer: Wow! Wow!

Respondent: I was motivated

Interviewer: Good to her that, so in a month, you can send how many?

Respondent: In a month, it depends, sometimes I even get 1 or 2 but sometimes they come even 5-6

Interviewer: And what are the age group?

Respondent: The age I have been sending is 4..., 5-18.

Interviewer: 5-18?

Respondent: I think below 5 is hard

Interviewer: Ok and the...then so, they come as outpatients in your place ehh and then you send them?

Respondent: They come in as outpatient, then I access them and I rule out other things and I send them

Interviewer: Ok, wonderful, now am interested in what you are taught about RHD, what do you think are the causes of RHD?

Respondent: I think is the, I could say it is congenital, some people are born with it but some due to the exposure of other things like sometimes for instance, those who come with too much

cough which maybe sometimes its poorly or untreated respiratory tract disease, so that is what I think and also sometimes I also think maybe some poisoning due to chemicals and others

Interviewer: Ok and the are you aware of the link between the sore throat and RHD

Respondent: Yes

Interviewer: Are the two of them associated or related in anyway, sore throat and RHD?

Respondent: Yes

Interviewer: How are they related?

Respondent: I can't explain much but to me I know there is some relation between the two

Interviewer: They are related?

Respondent: Yes

Interviewer: what were you taught that can prevent RHD, how can people prevent it?

Respondent: I think first of all to prevent this RHD does not start from now but it starts even when the mother is preparing for conception, how the mother is fed and how the mother takes medications like the folic acid and also these pregnant mothers are not supposed to take any drugs anyhow minus medical consent and then finally how the child is kept from birth.

Interviewer: Ok and then what were you taught are the treatment option for RHD? How is it treated?

Respondent: I may not know all but I know of PPF given once in a month and the time duration depends, it will be given but with a review, but for some people can take like 6 months, and some can go like a year or others even 2 years

Interviewer: when they are.....?

Respondent: When they are still getting their treatment

Interviewer: OK

Respondent: Yes

Interviewer: so do they ever stop?

Respondent: I have not yet known someone whom they have stopped the treatment because the program has not yet taken long here but for me I think they stop, that is my thinking, when the fault is corrected

Interviewer: Does it cure. The RHD?

Respondent: Yes to me

Interviewer: To you?

Respondent: Yes

Interviewer: And then, what do you understand by the long term prognosis of having RHD?

Respondent: The long term prognosis of RHD depends, for those who have realized and taken care of, the prognosis may not be very bad but for those ones that go unrealized, they end up with a poor prognosis

Interviewer: Ok, now tell me about your encounter with patients who have RHD, when did you last see one?

Respondent: I last saw one this year

Interviewer: This year?

Respondent: I think around September

Interviewer: September? Tell me, when that person came, how old is that person?

Respondent: This girl is 12 -13 years there

Interviewer: What symptoms did she have?

Respondent: She was having cough with chest pain and then I told the mother to bring her here, she was brought and when tested, she was found to be having it, the RHD and she was put on treatment, she normally comes back monthly

Interviewer: ok so you have told me you see many, you have not seen kids below 5 years, you only see those.....

Respondent: I think they are there, of course they are there maybe how they explain themselves is not easy but I have seen from 5 and above

Interviewer: Above to?

Respondent: Up to 18 mostly, last year or early this year, most of them I was finding people of around 16 to 17 years most common

Interviewer: Where they in school children?

Respondent: Yes they were school children

Interviewer: Ok and then do you think these patients, do they know the link or relationship between sore throat, acute rheumatic fevers and then RHD? Do they know the association?

Respondent: For them they do not know

Interviewer: So when they come to you, what do they say, what do they think is the problem?

Respondent: And the worst thing in the village, once someone has the sore throat, this person will go to the old woman, who will open the throat and do anything, yes, so to them they think the throat is having either the pus or its growing the oedemal and there is that local tonsillectomy they do in the village but we are trying to health educate them, others are understanding but others still go for it up to now. Like last week ah...,somebody was just about to take the child for that local tonsillectomy, then I told her, you don't have to take ,what you do, you first use these antibiotics, I gave, I gave metronidazole and Amoxicillin plus the pain killers and after two days, she came back to me and said the child took the medicine for two days and vomited pus and there was already improvement, I told her, did you take to the other woman, she said no, I didn't, so that child improved on that medication but its most common in the villages that by the time they are bringing a child to you, sometimes for me always when they come at times they hide it but the moment the mother talks about coughs and maybe ear and pain in the throat, I always ask have you done anything in the throat, and in most cases they would have done it

Interviewer: why do they always prefer going to that old woman, why do you think they go there. Why don't they believe they can be treated in the health center?

Respondent: I think its ignorance and how people started, they see that it helps but to me it doesn't because at times when that local tonsillectomy is done from home, at times it goes to some serious cases of septicemia and sometimes even the way it is cut, anemia sets in and even it claims the lives of very many children

Interviewer: They are dying?

Respondent: Yes

Interviewer: Is there anything done maybe to educate those old ladies, have you had the interaction with the old ladies where they do that?

Respondent: The problem maybe we can just communicate to them maybe when there is a radio program but those ladies, the traditional healers, they are not really very much close with the health centers and hospitals and you know with the nature of our work and the schedules, we are always busy, there is no way we can find them but anyway, we give the information to the clients who come, just as I can just say we give, there are those who take and there are those who don't take the information we give them

Interviewer: Ok and then basically, the symptoms you said they describe is chest pain, fever....

Respondent: Yes fevers, joint pains and sometimes cough which has taken long and throat

Interviewer: And then if you look at them, are they good at follow up and adherence, the RHD patients, in your opinion.

Respondent: They do

Interviewer: They do.?

Respondent: Yes

Interviewer: If you tell them to come for the injections, do you think they come?

Respondent: They do

Interviewer: What makes them to come?

Respondent: It's the way they are counselled, they well know of what taking place is and what may happen if they don't follow the treatment, they do come

Interviewer: What else apart from the counselling, what makes some people to come?

Respondent: Sometimes even from there I always tell them when they come ,transport is met like where I work as I told you, it's like 17 kms and the boda is 6000shs, so when you come and go, that is 10,000shs plus minus eating something but always when they come, they are refunded their transport, so it makes them come because sometimes when you are referring, they tell you, you see musawo,there is no money, there is no what...but when I tell them, you go ,the money you are going to use for transport, they are going to refund it.you know in the village, you can pick a boda and waits for you to take you back, so that is how they are like trying to like meetYeah, so the motivation is one, if you give them transport, two when you give them counselling

Interviewer: What else?

Respondent: Three is that, those ones who come to the hospital are those ones who care for their lives, so they take whatever advice you give

Interviewer: Any other, so how about those, do you think that there are those who don't come or who miss their drugs

Respondent: Yes it is possible

Interviewer: Why do you think some people miss their drugs?

Respondent: Some of them just take things for granted like that you are told to go back and you don't mostly when the disease starts, it looks very serious on the beginning of treatment, someone feels there is improvement and when they feel there is improvement, they think that they are healed then they will now miss to come and sometimes they forget the dates of appointments and others on realizing that they have passed laughs...they refuse to come

Interviewer: Why would they fear to come when they skip the dates of appointment?

Respondent: You know by the common saying, they say that for us the medics we are harsh because you are reaching here, the first thing I am not saying it has happened in the RHD but its common within health, not because the health workers are very bad but they know the implications of missing ,so of course definitely when you have passed by 3-4 weeks or even you have passed by 4-5 days, they will ask you why didn't you come on the exact date because even the reasons

they give do not impress the health workers like somebody will say I had gone to visit, such things, you find visit is not more important than health

Interviewer: Another thing just to take you back, have you encountered patients who go to those traditional, those elders in the villages who lied to you, when you asked them have you gone there and lied but you later discovered that surely

Respondent: Yes they are there, they lie, most especially with the middle age, they lie

Interviewer: They lie?

Respondent: Yes

Interviewer: Why?

Respondent: Of course they go there even when they are doing wrong things, they are guilty, they know it's not right and definitely they will not, it's not easy to start from there and because you are defeated from there and now you come to the health center

Interviewer: Ok, some of them lie?

Respondent: Yes, some of them lie but mostly mothers of very young children, they don't lie because they know when you don't tell the truth, it will not be well.

Interviewer: Ok, now then, how about those who miss their drugs when you give them a 30 days treatment, why do some of them not adhering to the drugs?

Respondent: At first I said, sometimes its ignorance, at times they forget the drugs, at times they have started feeling fairer than before

Interviewer: ok and then ah...what are some of the barriers or problems that you face when you're taking care of these patients, what do you think are the difficulties you get in caring for them?

Respondent: Ok we don't, actually in a health center where we work, we don't care for them from here because the drug is always taken there, we always refer them to come and get treatment from here, so to me I think we don't face the difficulties, the only challenge is that they don't come willingly to be accessed and referred by us, we talk a lot, health educate them and then they will start coming

Interviewer: Why do they resist coming here?

Respondent: Sorry

Interviewer: Why do they resist coming here, why don't they come willingly?

Respondent: No, they come willingly but sometimes they are not aware of the problems, in the most cases, they are not aware

Interviewer: Ok

Respondent: They are not

Interviewer: And then for other illnesses that you face, what are some of the barriers you get in treating these patients?

Respondent: One is lack of adherence, you like give treatment ,somebody goes to take it for two days, when there is improvement, she keeps it in the house, the next time another child is sick, she will start with the balance of the remaining drugs of another child unless the child starts feeling fair, it is stopped, two weeks later, the disease is back and the biggest challenge we have in the health setting is that the drugs that are provided by the national medical stores are not enough, they bring it like now and it has to serve for two months and at the end of one month's sometimes the drugs is even over, the remaining one month, they come when there is no what...,when there is no drugs in the health center and always patients when they come and go back empty handed, they will not come back until they hear rumors that the vehicle has passed laughed...,then....

Interviewer: The vehicle?

Respondent: The national medical medicine vehicle, then they will know maybe drugs are brought, let me go and check

Interviewer: So even they know the vehicle?

Respondent: Yes they know very well, that is why when drugs is brought, the population in the health center is too much, when drugs are not there, they will even relax, they become very few because they say even if you go, they will not give you anything, so that is the time they go to any drug shop and buy anything

Interviewer: So you told me usually when maybe those who miss appointments they come late, when they come to you, they say maybe we went for burials forgot, which other excuses do they give?

Respondent: Even I went for the visit

Interviewer: she went for the visit?

Respondent: Yes, those ones

Interviewer: What else, what else do they tell you

Respondent: Sometimes I had a burial but those ones are guenuine,at times I went for a visit, at times I forgot, at times I thought I had gotten healed, there was no more pain and what have you

Interviewer: Those are the excuses they give?

Respondent: Yes

Interviewer: Any other?

Respondent: Those are the few I can remember

Interviewer: And so, according to you, why do you think they don't come back apart from you said when they feel better, they relax, why, what else makes them not to come when they feel better? Your opinion now, what they tell you.

Respondent: To me?

Interviewer: You said when they feel better, they give up

Respondent: When they feel better they relax

Interviewer: what else, what other barriers are they facing in coming for the treatment?

Respondent: Maybe at times is distance

Interviewer: The distance?

Respondent: Yes, the distance, the weather, the climate condition

Interviewer: Which weather

Respondent: Usually when it's raining, like if it rains during day time, every activity is at stand still because in the village settings, they have ..., so you can't start moving in the rain that you are coming for your appointment.

Interviewer: So the weather condition, the weather, the distance and when they feel better, they don't come, any other that we have not talked about?

Respondent: No

Interviewer: Now let's look at the some of the local health barriers and we want to know which pieces are working for you and why and which ones are not working for you, when you look at the district administration and leadership, is it working for you, is it enabling you to do your work well when treating patients?

Respondent: Yes

Interviewer: How, why do you feel like it's working for you

Respondent: The district administration?

Interviewer: And the leadership, is it working for you, does it make your work easy while you are working?

Respondent: Yes, they do, like in lira district, me I can't blame any department because like in my health center, I always work hand in hand with them, I inform them of the challenges we have in hand in the health center and they always respond

Interviewer: They respond?

Respondent: Yes, like for instance in my unit, there was a lot of gaps but they helped me, the last one they had taken survey, there was no clean source of water but I know soon or later, it is going to be better and even my health center is heading to upgrading, actually they had even sent money but I think they diverted the money from up not from the district, they told us to wait for the next financial year, me I have no problems with the authorities, because first of all when it comes to lack of drugs in the unit, it's not them, no

Interviewer: Sowhat are the challenges you face in your administration, you know many cases come to your office, we don't have this, we don't have this, and how do you manage?

Respondent: The biggest challenge I face is lack of drugs and other utilities, but how do I manage, I have to just convince the clients to buy from outside because you cannot tell them and sit to wait for the drugs to be brought

Interviewer: How about the work force, the number you have in the unit

Respondent: The number is less but still it's from the ministry not from the district because the policy was passed long time, here is away they outline that in this level of health center, these are supposed to be the number of people working, although at the district setting, we still lack because we find some people whose names are there but they have gone back to school

Interviewer: So how do you manage patients with such challenges?

Respondent: We balance ourselves with the few who are there using the duty roster so that all the days are cover with work meanwhile while some people also have their rest because you cannot capture human beings and tell him or her to work from January to 31st December

Interviewer: Ok, and then if you look at the funding for health care in general, is it working for you?

Respondent: It's not ,it's not working for us ,for instance am going to give you an example like in my health center, the knowledge is there to treat also other diseases but the drugs is not brought like these days, the most common conditions I told you is the respiratory tract infections, some can go with the advice and counselling and then you treat it as automatic depending on the cause maybe when its viral but some need to be treated with antibiotics and we don't have it, even the few actually right now, the anti-biotic they bring for us is Amoxicillin, cipro an doxycycline and cipro they will bring like 500 and doxycycline also 500 to serve like for two months, then Amoxicillin they bring like 8000 and you know a tin of Amoxicillin on a serious busy day can get finished so that is like, its gets finished very fast actually me I suffer a lot because I always take pity on the patients, you find a very poor mother comes to the hospital sick and needs care but this is a mother who comes and find no drugs, you want to refer her, she does not have transport, she goes back and the sickness intensifies, sometimes it's even death ah...,like for pregnant mothers, my health center is in Amach subcounty,we have only 2 health center in our sub-county, from this small health center to the bigger health units, it's around 15 kms, you refer a pregnant mother, this mother

will not go, somebody is pregnant, do not have even a bicycle and cannot walk for this 14kms and she goes back and delivers from home

Interviewer: So those are problems that you encounter

Respondent: Yes

Interviewer: Ok, when you look at the time these patients wait before they are worked on, what do you have to say about it?

Respondent: The waiting time is long, right .it's just due to few staffs in place because the staffs are few but they will want to see everybody and definitely the waiting time at times becomes long

Interviewer: Long?

Respondent: Yes

Interviewer: And then when you look at the quality of services which patients get, are you satisfied?

Respondent: Not quite although we try but in situation where you are alone in the consultation room and you have 80 patients out, sometimes you tend to like hurry in order to serve everybody but in hurrying, you will not give quality services to the client because sometimes some of them need your time, you need to talk to them, you need to access them, you need to counsel them but if you do that, then you will not serve the rest and the rest will go back very annoyed, now in order not to annoy them, you hurry, but you know medically when you hurry, you do not give quality service.

Interviewer: And when you look at the qualification of the health workers you have, are they adequate?

Respondent: Yes they are above, there are those that are adequate and those that are not adequate, but the challenge is, as I told you, the policy we are using now was passed long time when the population was not like now, so you find now because of the few staffs, due to the staffing levels which is not from here, at times even the cadre that is not supposed to do something goes ahead to do it hence leading to poor quality service like for instance maybe clinician is alone doing now

some procedures, nursing assistant sits in the consultations, now nursing assistant cannot really access, diagnose and treat well

Interviewer: Ok, the medication you told me, definitely the drugs are not enough, and how about the diagnosis like in your health center, do you have like echo cardiography?

Respondent: The what?

Interviewer: Echo cardiography

Respondent: No

Interviewer: You don't have it

Respondent: No, actually echo cardiography in the whole of lira, maybe it's in two places, here and that one is it joint medical clinic, I don't know if there is any but I used to know only two.

Interviewer: Those are the two that you know?

Respondent: Yes and when you get out, you know its money

Interviewer: So in your center, do you have like any drugs like for heart failure drugs, drugs for BPG and anticoagulation drugs, do you have those drugs?

Respondent: No

Interviewer: No?

Respondent: Yes.

Interviewer: so patients from your area.....

Respondent: laughs....., really far,

Interviewer: So they have to come here.

Respondent: They have to come

Interviewer: And when you look at the guidelines and protocols for RHD care, do you have any here?

Respondent: The guidelines?

Interviewer: Yes.

Respondent: No

Interviewer: And how about, do you have the referral paths they have to refer the RHD patients

Respondent: We have the referral forms which have even the numbers, the telephone numbers and you can call ahead of time

Interviewer: Are they forms for the ministry or forms for the project

Respondent: They are for the project, I don't know if the forms is provided by the ministry but we received it through the project

Interviewer: Through the project?

Respondent: Yes

Interviewer: When you look at the medical records system and the way health information flows, are you happy with it, is it working for you in your health center?

Respondent: Yes, it is

Interviewer: Are the registries ok or is there any gap?

Respondent: No

Interviewer: Just in case someone wants to look at your records like for a year, is it easy for one to access the register or if I wanted to know like how many suspected RHD patients....

Respondent: Except that, ok I hear that it's a new HMIS tool, maybe its include that one but the old one we were using do not have the provision for that have the provision for that

Interviewer: And then if someone wants to track the suspected RHD patients or acute rheumatic fever that you had, would it be easy to get that?

Respondent: It will not be easy to get that because in the beginning even me I was not keeping the records, I could just fill the forms and I refer like that, now one time when they were asking how many are absent, I realized I was not keeping it, yeah and in the HMIS, once they find and whatever the provision for RHD is not there

Interviewer: Do you think it is very important to come up with the guidelines?

Respondent: It is very important because the ministry knows what happens in the villages through the reporting system but now since it's not there, we don't report it directly

Interviewer: And then what has worked for you in your health center, what are some of those local system health enablers factors that have helped you do your work well, administration, has it worked for you?

Respondent: Yes

Interviewer: Funding

Respondent: Funding no

Interviewer: Laughs..., health workers, numbers and qualifications?

Respondent: That one even no, what has worked for me is the attitude at work, the few members, the few staffs, they have attitude

Interviewer: Ok, what else has motivated you to keep working?

Respondent: The project always give some little token also although not regularly but that once in a while shows somebody is in care

Interviewer: Ok, let's look at the perception of patient's outcome, generally do you think the patients get the care that they need when they come to you?

Respondent: Yes, they do unless if the care that they need is not provided there that is when they don't get because you know when you come like when I come to you whole heartedly that you are going to help me then you tell me you see, your condition, I cannot work on it, you go to Mulago, now I will start things like how will I reach Mulago, even if it's the ambulance to take me, they will ask for transport, I mean the fuel, so it's not easy but services that they can get, they get

Interviewer: Ok, do you think that surgeries can be offered to RHD patients

Respondent: Yes

Interviewer: Do you do it around here?

Respondent: No, I have not known about it because I had a friend who had a daughter with the heart condition, the man even lost a land because I referred them here but the condition, no I think even the project had not yet come so they were taken to the health center cardio echo was done but from the private clinic and they were referred to Mulago heart institute and there, they asked them some good millions of money which he had to come back and sell of his land even his business has collapsed but thank God, the child is well

Interviewer: Wow! That is wonderful, and the patient's safety and the quality of care do you have any concerns? Are the patients managed in a safe way?

Respondent: Yes

Interviewer: why?

Respondent: sorry!

Interviewer: What are the reasons, why do you feel the quality of care they get and their safety is ok?

Respondent: Because I see they are happy and they recover

Interviewer: And then have you witnessed, do you think that there are some of the preventable deaths which are occurring in the health center, preventable that the person shouldn't have died but simply maybe there was some hindrance in the process?

Respondent: Yes, they are there

Interviewer: Any incidence that you recall?

Respondent: Last year around this time in December, the child was brought, the relative told me that they had a child who was not well, a child of 14 years, this child was taken to a certain private clinic, this child moving and he was shot from the chest with a ball and this was the child who was living with the grandmother, the child came back and did not tell the grandmother, after sometime he started feeling severe chest pain, they started treating the child everywhere with no improvement, the time I learnt of the child, he was in a private clinic on oxygen, they referred the child to lira hospital, then I called the acute rheumatic fever, they told us to bring the child, the

child was accessed but from here and they found out that the heart was normal but rather the problem was with the lungs and it had grown advanced, the child passed on from here

Interviewer: So do you think there are some patients who are dying in the communities without presenting to the hospital

Respondent: Yes, they are very many

Interviewer: Why? Why do you think so?

Respondent: I said earlier on that ignorance and poor health seeking behavior as some people in the village, by the way when you live in town, you don't know what happens in the village, drunkardness is rampant in the village and any father who drinks doesn't mind what happens in the environment, whether the wife is happy, the children are healthy, it's not his, for him, he is there, they are very many.

Interviewer: What do we do?

Respondent: We need to sensitize them using better channels maybe we can reach them over the radios, churches and whatever but they need serious sensitization

Interviewer: In your opinion, what are the two most common thing ministry of health should do to improve the patient's outcome?

Respondent: I beg your pardon

Interviewer: What are two most important things you think ministry of health could do to improve the outcome of our patients?

Respondent: First of all let the ministry prioritize health and put much funding on health, let them motivate even, I know it's a call, this medical profession is a vocations but even if it's a vocation, medics have families that must actually be seen after them and if the salary is little and you find somebody's child has to study but the monthly salary cannot even pay his school fees for one term, for you to pay the fees, you first have to keep on saving every months and yet in the family, you have to save, you have to build, you need to ...,those many things, maybe I would then in addition to others, let health professionals be motivated and cared for, by doing that, it will help them care for others, for example, I am going to give you an example, I know of a doctor who is my friend,

this doctor was first a clinical officer, he went back to school and did medicine, when he came back, he resumed work as a clinical officer, I think money was not enough for him, you could see him even rushing to part time in kitgum, sometimes he goes where but the moment, they gave him a position as the medical officer in lira district, he settled

Interviewer: laughs.....

Respondent: Yes, he settled, to me I think by that time he had started getting something that help him and the family minus running running, so he is settled at work, so I would think of first let the ministry look at the health workers with eye of mercy and secondly let them look at the community with the eye of mercy, they put things in life, the preventive measures and also the curative measures like for instance when the IPV was brought, somebody came from the ministry and he was bitter whenever he sees the number of children getting DPT3 more than those getting IPV, he was harsh on them but do you know what happened, when he went back immediately IPV is out of stock, so they want us to do things but they are not providing us with what to use, just of recent, the Rota virus was not there and yet they are telling you every day to give ,now what do you expect?, nothing good

Interviewer; Ok thank you so much, anything in particular for RHD that ministry of health can do?

Respondent: Yes, first of all, let them sensitize the community by using whatever means but the means that make the information reach every community wherever they are and secondly, let the medication be provided at least to avoid the issues of coming from the village to get treatment and find when the drugs is not there and definitely when the drugs is not there, they don't go and buy not because they don't want but at times because they don't have money and even if they go and buy, you can't just trust where they buy it from, in a drug shop where drugs are kept, somebody flaws somewhere, you may take even the right drugs but when the drugs has expired and it will not work out, so let them at least and let them sensitize and provide it

Interviewer: anything else before we stop here

Respondent: I am just grateful to the project and I am happy with the steps you have taken, I know with all these words we have spoken here you will not take it for granted, I know you will take it where it should go and the steps will be taken.

Interviewer: Ok, thank you for your time and your wonderful views, we shall definitely use them to make sure that better programs come up to prevent RHD and control it

Date	15 th December 2018
Interviewee	HW 007- Lira
Age	█
Designation	Nursing officer
Venue	Senior Nurse's room – Lira Hospital
Interviewer	
Length of the interview	47:07

Interviewer: So you are welcome sir, thank you for giving us this opportunity to talk to you. Like we said we are going to share information; you will give us your views about some of the local barriers and enablers to RHD prevention and care. Umm, today is the . . . for record purposes, today is the 15th and we are seated here in the senior nurses' office in Lira hospital. So just tell me about yourself, how old are you sir?

Respondent: I am now █ years old.

Interviewer: Can you tell me about your qualifications?

Respondent: I have a █.

Interviewer: Where did you train from?

Respondent: I trained from █.

Interviewer: Okay. █, is there any other training you got?

Respondent: Not so quite; █.

Interviewer: █?

Respondent: █.

Interviewer: Okay, so when did you qualify as a . . . ?

Respondent: As a nursing officer?

Interviewer: Yes.

Respondent: In █.

Interviewer: And how long have you been working in Lira hospital?

Respondent: It's now █ years

Interviewer: Okay can you tell me about the demographics of the patients in your practice; who are they? What age group? Are they women? People you have been seeing and the common illnesses.

Respondent: That cuts across because, you know for us in the nursing division, we keep rotating. Like, sometimes back I was in the children's ward, and then in the surgical ward and right now am in the medicine ward.

Interviewer: But the biggest number of patients are typically what? Are they adults? Are they children? Are they male or female?

Respondent: They are almost equal but when we consider sex, it is more females than males.

Interviewer: What explains that?

Respondent: To my understanding and basing on my experience, you know ladies seek medical care earlier but men tend to remain behind.

Interviewer: Why do you think men tend to remain behind?

Respondent: To my understanding, okay what has been in practice, men have that tendency of denial. Until they are very sick, that is when they accept to go to the hospital but with ladies, the moment they feel any pain they rush to the hospital. Men instead have that tendency of denial until maybe when they are down, and that's why when they are admitted they don't even take long because they normally come at a late hour or stage.

Interviewer: So how can we help those men? How can we make things better?

Respondent: It's not very easy but we just have to keep advocating. The few who come, we have to tell them the benefit of early treatment.

Interviewer: Okay thank you. And what are the common illnesses that you see here?

Respondent: In my unit in the ward here or in the hospital?

Interviewer: The hospital and the ones you have come in contact with.

Respondent: Okay. Let me just be specific to the unit now where I am working. Here we have malaria cases, hypertension, diabetes and some few Rheumatic Heart Disease but those ones basically associated with hypertension, and pneumonia and the rest are HIV related.

Interviewer: And then tell me about your training on RHD; Rheumatic Heart Disease. Have you received ant training?

Respondent: That one was way back in school but I've never got any refresher.

Interviewer: Okay, so since graduation you have not had any refresher courses in RHD?

Respondent: No, though I've been in contact or seeing patients but with that old knowledge from school.

Interviewer: Have you had any challenges in handling these patients given that you have not had any refresher courses on RHD?

Respondent: Umm, not so quite. You know in most cases these patients are seen by doctors and they write a prescription and the moment the prescription is made, I only implement the treatment.

Interviewer: Okay. Have you had any CMEs here about RHD?

Respondent: It has always been conducted but in most cases I didn't attend, otherwise the CME about RHD had been conducted.

Interviewer: What could have been the reason you didn't attend?

Respondent: Sometimes, like at the moment whenever . . . since I started school, our CMEs are always on Thursday and Thursday is when I always travel to school. That's one, and then two; sometimes I may be around on day duty and by the time the CME is going on, I have to cover the ward also.

Interviewer: I understand. So in a week, let start in a day; how many RHD patients do you see?

Respondent: In a day?

Interviewer: Yes.

Respondent: On average I can see one.

Interviewer: And in a month?

Respondent: In a month it can be three to five because those are cases . . . you see, since we rely on admitted cases, and what I mean are those ones admitted on ward, on the ward we may have at least three to five, but it has never gone beyond five.

Interviewer: Okay. Then outpatient?

Respondent: For our patients I can't explain.

Interviewer: And then if you look at the demographics of the RHD patients, where do they lie; males? Females? Adults? Children? Most of them are what?

Respondent: Mainly children, and to the best of my knowledge now that I surface with them here, I have seen females, but the younger ones and not the elderly.

Interviewer: So the ones you have seen most are mainly inpatients!

Respondent: Yes.

Interviewer: But if you compare them to the number of outpatients, which number is greater?

Respondent: I believe the number of outpatients is greater because most of the time when we discharge them, we tell them to come and attend OPD.

Interviewer: Now I am interested in what you have been told. What is your understanding of RHD? If you can use that logic you got at school.

Respondent: If I am to recall, Rheumatic Heart Disease is an acute heart disease that an infection which is caused by bacteria which basically affects the heart valves. That's how I remember and I've forgotten the type of bacteria which causes that.

Interviewer: Are you aware of any link between sore throat and RHD? Are the two related?

Respondent: Exactly. When I recall, when a patient develops tonsillitis or sore throat then they do local tonsillectomy, definitely they can predispose or complicate to RHD.

Interviewer: And then, what were you told can be done to prevent RHD?

Respondent: One is; umm, seeking early medical treatment and then treating respiratory tract infections early. And the, umm . . . that's what I still remember.

Interviewer: Okay, you said people do local?

Respondent: Tonsillectomy.

Interviewer: Why is it like that? How come people first go for that before they come to the hospital?

Respondent: You know there is a local belief in the village, well it's not a local belief but there are people in the village, these traditional healers. So because of the . . . you know when we talk of tonsillitis, there's that inflammation of the tonsil bed there, so the moment they see those white parts, there are people who tend to remove locally. In the village, they are specialized in that, so the moment one has difficulty in swallowing or has pain, they first go to them to consult and when they check, they remove the pus, and some of them improve much as those people do it locally. That is why we are talking about local tonsillectomy; they do it locally not even under any preventive precaution.

Interviewer: Okay, then what is your understanding about the long term prognosis of RHD?

Respondent: The long-term prognosis of RHD! To my understanding, now that probably the heart valves are already involved, definitely it may not be very easy for the valve to recover its natural potency. That is what I just understand, because the valve is already damaged unless maybe when there is an optional way of making a transplant. So we just now keep controlling the complications.

Interviewer: Okay. Tell about your encounter with an RHD patient; do you recall the last patient you saw with RHD?

Respondent: Yes, I remember there was a young girl on ward here.

Interviewer: So tell me about that visit; how was she, what did she present with?

Respondent: The girl was feverish and actually presented with some elements of difficulty in breathing and she was also somehow emaciated. She was emaciated and would complain of easy fatigue, but she was able to walk but the moment she walks she would get fatigued, but she wasn't gaining weight.

Interviewer: So how did you handle that patient on ward?

Respondent: It was the doctor who handled the patient but there was a time when the hemoglobin levels were reduced until we transfused, and I remember I have been giving some antibiotics and . . . I don't remember all.

Interviewer: Now, what is the average age of your RHD patients? You said you have mainly seen women and children, so under which age group?

Respondent: Below 12

Interviewer: And the women?

Respondent: Those whom I saw on ward here, they were old . . . okay, umm women . . . women [thinking], I remember there was one who was elderly but few of them are elderly; the majority I saw are younger ones.

Interviewer: When you look at them, are they working class?

Respondent: No, they are just from the village.

Interviewer: When you look at their profile, do you think they are learned? Do you think they went to school?

Respondent: umm, those who I encountered didn't go to school. Maybe if they went, then they stopped at a lower level.

Interviewer: So do you think they are aware of the link between sore throat and RHD or Acute Rheumatic Fever? Do they know that association?

Respondent: They may not know it until maybe we organize something like a health talk. At the ward, we educate them; we tell them, but I also believe that from entry point, they might be . . . Since they are now our clients, they keep coming so I believe that even at the entry point they are always told the causes or how this condition comes about. But for us at the ward, generally we gather these patients and talk to them in general; if we choose to maybe talk about RHD, we talk to all of them and even those with different conditions.

Interviewer: So how often do you talk to these patients on the ward?

Respondent: Umm, normally, okay I am the In-charge of this ward, so I normally, at least twice a week. After seeing a common conditions, or in most cases we talk about hygiene, but after seeing maybe common conditions, I share with them but briefly like for some ten to fifteen minutes.

Interviewer: So do the topics keep changing or they depend on the diseases that are common on the ward?

Respondent: I don't have a schedule, but ideally I have to set the program, but I have to first see what disease is very common on the ward, and then I remind them about it. But basically as I said, it's about preventive part of it, like the hygiene and malaria. So that one is the most common one.

Interviewer: Like if you looked back in the last 6 months, how many times did you talk about RHD and sore throat and the need to treat it?

Respondent: To be honest, I've never talked to them about that, about RHD. But with the issue of local tonsillectomy, I have talked about it. I have ever told them that the moment you discover any pain on swallowing, instead of going to those local people, come to the hospital. And if am to recall, you were asking about the last six months?

Interviewer: Yes

Respondent: No, I think I talked once.

Interviewer: So at what point do these patients come to the hospital? Let's start with those with sore throat; when do they decide to go the hospital?

Respondent: After facing the challenge, after removing, okay they come with septicemia and some of them with already reduced HB, anemia and definitely we start them on antibiotics right away.

Interviewer: What kind of symptoms do RHD patients describe to you when they come?

Respondent: Sometimes that history of sore throat is there but they sometimes come when they are even treated and they experience evening fevers and some chest pain and some bit of difficulty in breathing and fatigue with tiredness.

Interviewer: Those are the symptoms that they usually describe?

Respondent: Yes, but that fever and the pain; some of them talk about the pain of the joints.

Interviewer: Okay, umm when you look at their follow-up and adherence, when you call them to come back for review, do they come back?

Respondent: umm, the challenge now, I think they have been coming because we only keep them on the ward when they are admitted. But because these people are there handling themselves, they just come and attend OPD and then they go back, but I always see them coming but right now we are handling those who are already admitted.

Interviewer: For those whom you have encountered, what's your sense of their adherence to the treatment?

Respondent: Well, when we admit them they don't take long. You see, we now consider as their disease now, so they come when they break down; when they are not in good condition. So after stabilizing from the ward, they normally go back home.

Interviewer: So what sort of barriers do they state getting care they need? What stops some of them from coming for care?

Respondent: umm, okay; maybe, I am just assuming, in a local setting when someone feels they have improved they relax to come back. This also applies to other disease conditions; whenever they feel better they relax coming back until again they break down.

Interviewer: What else do you think explains their failure to come for care that they need?

Respondent: Some of them operate from far and they may claim that there is no means of transport or that there is no one to bring them, like the young ones; they depend on the parents. Another thing is . . . but those are the things.

Interviewer: Okay, and then umm, so those are the two things you think are hindering them from seeking treatment!

Respondent: I don't whether, because finance is also another reason; sometimes when they do have money but that's also linked with transport. And also staying here; staying in the hospital is also not very easy because they need to organize themselves to get some money to sustain themselves.

Interviewer: So for those who manage to come, what do you think really enables them to come and also adhere to treatment?

Respondent: Now, the issue is; it also depends on the how they perceive the information because when we are sending them home we will instruct them to come for follow-up and people who understand come.

That is one, and two; they also understand the benefit of coming back for refill, so they also come because they believe that when they are treated they improve.

Interviewer: So understanding benefits and also the information you give!

Respondent: exactly.

Interviewer: Okay and then what else?

Respondent: umm

Interviewer: some come

Respondent: Yeah

Interviewer: So we really want to learn from those who come back; what motivates them?

Respondent: Like I said, because [clears throat] some come back because they want to improve. Actually they want to get cured.

Interviewer: Okay. And then, let's look at the local health system barriers. We would like to which of these pieces we are going to talk about are working for you and why. If you look at the administration and the leadership in the district, how is it? Is it working or not?

Respondent: In relation to their care?

Interviewer: In relation to the treatment and the way you do your work here as health workers. Let's look at the administration here, when you look at it, is it favorable? Is it helping you to do your work well?

Respondent: [laughs sarcastically] Yes, I could say yes.

Interviewer: Why? What makes you feel like it is working?

Respondent: Because whenever we make orders or requests, like in most cases the supplies, they are always available as far as patients' care is concerned; and supplies and medicine.

Interviewer: So the medicines you have them! If you talk of the RHD medicines here, how is the supply?

Respondent: What our patients benefit from the hospital is just to treat the symptoms, the supply is there like antibiotics and the pain reliefs.

Interviewer: How about the leadership in the district, what do you say about it?

Respondent: That one I have very little to say.

Interviewer: We can bring it to the health leadership in the district; how is it?

Respondent: With that I have very little to say. There was a day I saw the mayor of the municipal who as just passing around asking, "How are you handling your patients?" He was friendly, so he just came and passed around the ward and was emphasizing, "Do you have drugs?" "how are your patients?" "do you have any problem?" and then we just shared with them but I didn't see any outcome or any promise, but at least since I came here, at least I saw them appearing once.

Interviewer: In five years?

Respondent: Yes, they may be coming here when I am not around because we also rotate duties.

Interviewer: Okay. When you look at funding for healthcare in general, what is your opinion about it? How do you look at it?

Respondent: The funding for healthcare, to me I think is very minimal because the supply is always inadequate and the medicines written, they normally buy the cheap ones but there are other expensive drugs that the government doesn't send, and it's us now to write for the patients to go and buy from the local pharmacy around?

Interviewer: So for the expensive ones, they are not given!

Respondent: Yes, I think because of the wider hand, they tend to just resort to those cheap drugs.

Interviewer: Okay, they only give the cheap ones.

Respondent: Yes.

Interviewer: Okay. And then, how about RHD funding in particular! What is your opinion about it?

Respondent: Since I am not directly in touch with the project, I don't have anything to say about that except to us, like in government or on the ward, as I told you we just give what is available.

Interviewer: Okay. So when you tell them to go and buy the expensive drugs, what do you think happens?

Respondent: Some of them buy and some don't; they say they don't have the money. So that's the challenge.

Interviewer: So how do they move on from there?

Respondent: That one is now very hard for us.

Interviewer: Now if you saw five patients and they are all referred to get expensive drugs, how many would afford to get the drugs from the pharmacy?

Respondent: They are buying.

Interviewer: They buy?

Respondent: Yes, like four out of five, I think four can buy. It's a matter of telling them the benefit of the drug and like me in particular, I always encourage them. I would say, "Please, life is life and the moment you lose it, there is no where you can get. So you have animals at home and other things, you go sell like a goat so that you are able to buy the medicine because the government is unable to supply all that is necessary." So when I, actually let me use the word 'convincing'. When I convince them, they understand and go and buy.

Interviewer: Like typically, how much would someone spend if he has to go and buy the drugs in the pharmacy?

Respondent: For?

Interviewer: For maybe RHD drugs, like how much would they spend?

Respondent: I can't specify that because it depends on the type of medicine prescribed.

Interviewer: On average?

Respondent: Some if they have been prescribed antibiotics that we don't have, they can spend like 20,000UGX.

Interviewer: Okay. And then let's look at the number of health workers and qualifications; if you look at the numbers in the hospital here, how are they?

Respondent: The health workers' number is great but the challenge, you find that . . . well the number is high but on ground they are few because some are on released for school and some have other outside programs, and some are in administrative, and [clears throat] there are others who are also due for retirement.

Interviewer: So now that they are few especially on ground, what are implications on these patients?

Respondent: The challenge is now workload and the patients are not accessing the quality service, because even right now I am here because the person who was supposed to cover duty has been taken to another unit. So I have to come work and give a hand because we don't want the ward to remain without anyone. So the number is very low; others are leaving for school and others for their leave, like that.

Interviewer: And then when you look at the qualifications, how are they? Do they match with the need?

Respondent: To my understanding the qualification is okay except the challenge they are facing now is that some body may upgrade and get another qualification but they are not motivated or promoted. That is the challenge, but the qualification is there.

Interviewer: And then, do you have any RHD specialists around here?

Respondent: I don't think so.

Interviewer: You don't have?

Respondent: No.

Interviewer: And do you have any nurses that have been trained?

Respondent: No.

Interviewer: So how much time do these patients spend when they come for visits here, maybe like for follow-ups? Do you have any issues with attendance?

Respondent: When they just come for follow-up, they are just reviewed there and then since the number is not much, and then they go back. They don't take long except if they are admitted; that's when they are kept on ward and they take like three to five days.

Interviewer: So for medications like heart failure drugs and those things, you said you don't know much about them! I know you said that most of the expensive drugs are not there, but do you have the diagnostics here, or maybe if you want to do ECHO Cardiograph for instance?

Respondent: That one is there.

Interviewer: You have it?

Respondent: Yes, we have it.

Interviewer: And do they access it free of charge, the patients?

Respondent: They do it freely.

Interviewer: Okay. If you look at heart failure drugs, how are the stocks here?

Respondent: umm, we have but not all.

Interviewer: Not all!

Respondent: Yes

Interviewer: Then DPG and anti-coagulation drugs, are they available?

Respondent: No.

Interviewer: No they are not?

Respondent: No.

Interviewer: Okay. When you look at the way you handle health information here, the medical records system, how is it? How are the registries? The outpatients, the inpatients and how are they integrated; how do you look at your medical records system, like the flow of information among the different departments?

Respondent: Yeah, it depends on the individual ward, like for us in the ward, okay for every new addition, every patient admitted is registered in the admission book and on discharge, and umm we also exit from the admission. Their files are kept in the registry

Interviewer: Okay. So just in case a patient who was seen like three months ago comes back and you need to refer to their file, is it easy to retrieve it?

Respondent: Yes, it's easy because when they are going we just give them the discharge form and there is a number in the file which we normally write on the discharge form. So when they come with it, we just refer to the registry.

Interviewer: Any areas that need to be improved in your medical record system and the flow of health information?

Respondent: umm, maybe the challenge is, it is the same health workers who attend to the patients on the ward that are the ones who keep the records of the patients on the ward. If there is need, at least a records person has to be at least on the ward to help us. I think that would also help more because we are not very perfect in record keeping.

Interviewer: Okay, I get it. Now, umm do you think there's a registry of RHD patients here and those who have Acute Rheumatic Fever? Have you ever come across that registry?

Respondent: It's those people who normally handle them but for us in ward, we usually mix them with the rest of other patients. We don't handle them separately.

Interviewer: So let's look at the local health system enablers. Which pieces are working for you; administration, funding and the number of health workers? Where do you give a tick here? What has made you work easy here? What has worked for you?

Respondent: What has made our work easier?

Interviewer: Yes, what has made you do your work?

Respondent: Now being a civil servant, either you are recruited or employed, we are mandated to fulfill our duty. We are guided by our roster; we make our roster and keep following it.

Interviewer: So do you have any guidelines and protocols on RHD care?

Respondent: No.

Interviewer: And do you have any referral path that if you get an RHD patient this how you refer them and this is where they are referred to? Do you have any in place?

Respondent: umm, let me not lie there; we only see, because we have a doctor on the ward, so we sit and discuss but we have never got any serious complication that made us to refer.

Interviewer: Let me look at the administration; is it working for you? Is it favoring you to do your work well here?

Respondent: Fairy well?

Interviewer: Funding?

Respondent: No. For us now, like when the month ends and we get our salary, we feel like we are being motivated but on ground, there's nothing; we only rely on the salary.

Interviewer: So for the health workers you said the numbers are quite few!

Respondent: The number is few.

Interviewer: Medication, you said?

Respondent: It's normally inadequate.

Interviewer: Then the medical record system?

Respondent: They are trying but people are also struggling with them on the ward here; keeping a record on the ward, and I was looking if they can also . . . but we are doing it.

Interviewer: So for you, what has motivated you? At least you get your salary at the end of the month!

Respondent: Yeah.

Interviewer: And then in your training you are obligated to do your work!

Respondent: Exactly

Interviewer: Anything else?

Respondent: I love my work.

Interviewer: Generally, do you think patients get the care they need here?

Respondent: Not all because there are other whom . . . when I was telling you about shortage of drugs, when you write for them to go and buy and they don't have money, they feel like they are not cared for. They feel that the hospital is not working on them and yet we just don't have.

Interviewer: How about those who need surgery, do they get the care they need here?

Respondent: Yes.

Interviewer: They do?

Respondent: Yes.

Interviewer: Now like RHD patients who need surgery, do they get the care here?

Respondent: No. there's no . . .

Interviewer: Now what do you in case they need surgery?

Respondent: Patients with RHD here, I think they are referred to Mulago.

Interviewer: How do you look at the patient's safety and quality of care they get here? Any concern?

Respondent: The patients' safety, I think it's okay.

Interviewer: And the quality of care they get?

Respondent: That one is not to the maximum because, you see much as we are caring for them, but we are again requesting them to buy drugs. That means the quality is not adequate because we don't have other supplies which we request them to buy at their expense.

Interviewer: Have you witnessed any preventable death here in hospital? You look and you say surely this shouldn't have happened but it has happened.

Respondent: No I've never seen.

Interviewer: You have not seen any death were you say you we could have done this? Maybe a constraint?

Respondent: No, I have never seen.

Interviewer: Okay do you think there are patients who are dying in the community without coming for care?

Respondent: Yes. That's because of ignorance and some people believe in prayers, some people believe in local medicine. They are still there though not many.

Interviewer: So in your opinion, what are the two most important things Ministry of Health could do to improve the outcomes in our patients? What can they do?

Respondent: To improve outcomes!

Interviewer: Yes, of the patients such that instead of death we see people recovering.

Respondent: In first place those who are working should be motivated in form of allowances and the rest of it. Then they should also recruit more health workers, and then adequate supply of the medicine. That can really improve very well, and then advocate the mobilization of community about health seeking behaviors.

Interviewer: And then, before we stop, for RHD in particular, what do you think they should do to improve the outcome in RHD patients?

Respondent: Okay, for RHD, to me I would . . . because now we see how it's being managed by the project, so I would expect it to be integrated. They could restart with the medicine, you know, if we can get a refresher knowledge on management and the supply of drugs specifically for such conditions. If the supply is adequate and with knowledge, I think they will really pick up or improve very well, it should be sustained.

Interviewer: Okay. Anything before we stop?

Respondent: No. I think that's all.

Interviewer: Thank you so much for giving us this time and this great information which we shall use to make sure that we improve the health outcomes of our RHD patients.

Respondent: You are welcome.

Participant ID	HW 008 - Lira
Age	■
Date	18/12/2018
Venue	LRRH
Interviewer	

Interviewer: Good afternoon,

Respondent: Good afternoon,

Interviewer: Thank you for accepting to be part of this study, we would like to determine how to better provide the care for patients with RHD, so we have a few questions to be going through. There is no right or wrong answer, so feel free to answer every question and then every data collected will be confidential and it will not be linked to your identity for any comments made. Ok, so tell me about yourself

Interviewer: How old are you?

Respondent: Am ■ years old

Interviewer: Ok, your qualifications?

Respondent: I have a ■

Interviewer: Ok

Respondent: ■ at lira regional referral hospital.....

Interviewer: Ok, where did you train from?

Respondent: I did my ■

Interviewer: Ok, how long did you, when did you qualify?

Respondent: I qualified in ■

Interviewer: Ok, so how long have you been working here?

Respondent: ■

Interviewer: [REDACTED]?

Respondent: yes

Interviewer: But [REDACTED] in total

Respondent: Yes

Interviewer: Ok mainly about your work environment, which patients do you usually see?

Respondent: You know as emergency department, we have to, and we are supposed to strictly work on emergency, casualty then critically the ill patient but as you work in the hospital, you have to go on and do the policy of the hospital. The policy of this hospital says that every patient who is admitted in this hospital must pass via emergency and therefore we see a wide range of patients, we get the casualty, we get the accidents, we get the critically ill and then any other patient that the doctor sees, wants to see and the availability of the doctor is there in the emergency ,we allow them in .And that is why am saying our emergency and casualty department in lira is quite different because we go with the policy of the hospital, that is what they thought would meet their criteria

Interviewer: Ok so all those, which are the common illnesses that you...come across in your day to day care

Respondent: Yes, the illnesses apart from the accidents, the illnesses we have are mostly medical, that tense comes so much, during Tuesday, that is the clinic day, these days we get patients of hypertension, diabetes, we have the many heart issues, the RHD and ah...we have cancer patients who come and then we also have the patients with liver cirrhosis, those are the ones that are quite many in our registers meanwhile there are also other cases and then of course HIV patients, they come

Interviewer: Alright but then what of by age group, which age group do you usually accept into your department?

Respondent: we do accept any age group

Interviewer: Ok, also it cuts across

Respondent: It cuts across both children, adults and elders

Interviewer: Alright, tell me a bit about your training on RHD and did you receive any specific training at school?

Respondent: On RHD?

Interviewer: Yes

Respondent: We did RHD when we were doing medical surgical training

Interviewer: ok

Respondent: And we did it just as a disease, I did it in my training as a disease but not as a specialised course or workshop or anything and then as a nurse, we go so much on the nursing care, part of the areas of RHD because that is where we so much dwell on

Interviewer: Have you received any training since graduation?

Respondent: On RHD?

Interviewer: On RHD

Respondent: No

Interviewer: No?

Respondent: Not

Interviewer: Ok, how many patients with RHD do you usually see like in a week?

Respondent: In a week. Ohh my God, the numbers, they were few and because it wasn't so much of a concern when I had just come they were a little few and they came in and some got out un recognised, we just register them like that but eventually when this research study came in and there were people around here who really created awareness, I would say so it really raised the number so far in a week, a part from those ones coming on the treatment, we can get like 13-14 and most of them are children

Interviewer: That is quite a big number

Respondent: It is

Interviewer: Yes, so are these inpatients or outpatients or both combined

Respondent: I would say outpatient are more in number because most of them came in as the awareness was created and so they come in when they would be managed from home, they just come for their treatment and go back but the inpatient are always few, they are like 5-3,like that

Interviewer: Ok quite interesting

Respondent: Yes

Interviewer: So, something like about what you were taught, what is your understanding of what causes RHD?

Respondent: The cause as now as a medical personnel of course, I know its caused by streptococcus the bacteria that causes RHD and briefly what I learnt from it is after getting that infection as a sore throat gradually when not treated which is mostly not treated in our culture, they do whatever they feel in the community, so when someone goes into RHD and once you get this disease, it's not their own act, I know there are specific parts that they attack ,the reason why they attack those very parts am not very clear with it or conversant with it **but** I know there are tissues that they like and they can dwell on especially we have the neutral valves that normally they go there and settle there and cause the scaring of neutral valve, and there are also another valve, I think that is the noetic valve, there are two valves I know but am not sure about it.I know that when this disease is not treated and it stays in the heart, that is what they do and they cause the scaring and once the scaring takes place, then there is a weakening of the valves and then there are many things happening, complications start coming in but now according to my training, I know that with antibiotics, these conditions can be handled, it can actually clear and once you are getting treatment, I know it's not about anti biotics **you** can be given, if complications starts like joint pains, the sore joints, then those ones you are supposed to be given anti-inflammatory and I think it's choice of aspirins which sometimes is given in a little higher doze. others go, if its severe, they even add steroids as an anti-inflammatory, that is what I know and other heart drugs I don't want to talk about them because am not sure but that is what I know as a nurse that I should also see that my patients receive them despite my nursing care plan and then in the nursing care plan, as I plan for my patients with RHD? What am i supposed to do? The aims of management are like four, one is to relieve the pain because they come with pain and then two is to allay anxiety, they are very anxious and then three I have to make them to, to how do I say, you know they always complain of getting tired so I have to get away of making them gather some strength and see that they can do an activity at a time and then of course the last one creating awareness, counselling and making them, know what it is health education and what causes RHD, those are my four aims of management

Interviewer: Thank you so much, so are you aware of the link between sore throat and RHD?

Respondent: Yes, I do, am aware about that

Interviewer: Ok, what do you know about it?

Respondent: Yes just like I said, when children are growing, deaths normally occurs so much in children though some adults do get sore throat as well, but I have seen children, very many children, children who are coming with sore throat and once they come with sore throat, normally those one who turn to the hospital get a better chance of getting anti biotics but there are those ones in the villages that they believe that scrapping those sores in the throat and creating wounds and then just give them mouth gaggles, sometimes you are just treated with local medications is also there and what does this take, it eventually leaves the bacteria to travel where they want to go. Here is a spread of the bacteria system basically and once it goes in the system, the heart faces with paths that when they reach in, they cause a problem and that is what I was saying that they go to the heart and I don't know why they like the valves, that is what I know about that

Interviewer: And what were you taught that can be done to prevent RHD?

Respondent: In the prevention of RHD, one, we are taught of oral hygiene and when we were giving health talks to the community, we need to talk about their oral hygiene and then also knowing that there is already a problem, a child is complaining of pain in swallowing or even tells you that there is a kind of itching in the throat, you must seek the medical attention because once they go to the hospital. It will be checked and then the other thing is proper nursing care or proper medication

Interviewer; So, you mean by properly treating the sore throat?

Respondent: Exactly

Interviewer: OK, what else

Respondent; What I can talk about also by doing investigations to check because now we know from that there can be a problem and so we needed to do this to check the state of the heart to check systematically if there is still the bacteria in the system, then further management is given

Interviewer: ok and then do you know about the treatment options for RHD?

Respondent: Yes, right now what we are given, not even as I was trained, **they** said the best drug that could clear streptococcus not only for RHD but the drugs that clears the streptococcal is the Benzathine penicillin

Interviewer: Ok, so how often is it given?

Respondent: We give monthly to the patients but about the diseases, it's given by kgs, it's calculated per kg

Interviewer: Any other treatment option

Respondent: For RHD?

Interviewer: Yes

Respondent: Am not sure, a part from the antibiotics which is the major drug and the anti-inflammatory that we have talked about, the aspirins as an anti-inflammatory built in rare cases, we go even to give the steroids

Interviewer: Ok, alright then what is your understanding about the long-term prognosis of RHD?

Respondent: Wow! It's not very nice both laughs, the prognosis is good or the few patients we have seen with treatment, their prognosis has been good especially those that come in the early stage when complications haven't started so but issues about prognosis despite that am a nurse. I know that there is an author of life both laughs....so it's a bit of trick because it's funny not funny though but some of our patients even when you talk to them **and** we give them treatment and they have gone home when they miss out on whatever we have told them, days will leave you and that of the prognosis should have been better, comes back later when it's worse and so it's both sided from my side, I may see that the prognosis is going to be fine because the way I saw my patient, I know that my patient can pick up but the other side, as we manage, other people don't take it in the way we told them to do.

Interviewer: They don't follow whatever

Respondent: They don't follow and then therefore the prognosis starts to be bad

Interviewer: Meaning for those who don't appear for the medication the prognosis is bad and those ones who really adhere to their treatment

Respondent: Exactly to their medication and follow up days

Interviewer: Ok could you tell me about the last patient you saw with RHD

Respondent: like both laughs...yes this is interesting, I think I will talk about my own patient. I think it's very unfortunate that whatever you are the medical personnel, there are things you don't miss out, I used to see those patients and I used to manage them as they come to the clinic, but the last patient I saw is my own daughter, who is the daughter to my brother and she could tell us that she gets tired but she never told me, she could tell her friends, you people I get tired very fast when they are running in the stairs, she complains and they took it for granted but one day when she came with palpitations and I saw her losing weight, from school then when she came she told me, I also get tired very fast, she could not tolerate many activities so I gave her to mop the house, as she was she was mopping, I saw her get palpitation and sweating, that is when I realised that she is not fine and when I brought her to the clinic to be checked, they told me that she has a RHD and that was very bad for us, it was not a good news, so that is the last patient I saw

Interviewer: So other than the easy fatigue ability and all that, was there any other symptoms she was complaining about?

Respondent: Yes, eventually when I asked her she told me she had the ankle, ok she was first at school, when she was in her O'level, she could get swellings on the legs that could start from the ankle and then comes to the knees but it doesn't reach the knees and then when we give an anti-inflammatory it goes back, the other time again the thing comes and we could not think we were treating her as light, or other thing some even said she was charmed, so we had those issues with her until when we were told she had RHD, that is when now we started reflecting on the symptoms and signs that she used to tell us because she could get those things even sometimes without fever and then fever comes, like that and then when I talked to the mother, the real mother, she told me that she had sore throat twice when she was in her primary and she got symptoms of getting tired very fast at that time but eventually treated her with malaria and they said she is stable

Interviewer: Ok

Respondent: Yes

Interviewer: But I hope she is doing well right now

Respondent: When she started her treatment in the first week, she wasn't fine, she was anxious, the anxiety made us not to see any improvement

Interviewer: laughs

Respondent: Not until she got her second doze with the counselling, now she is fine

Interviewer: That is good to hear

Respondent: The pain has gone, she is happy, she is feeling well

Interviewer: Ok so what is the average age of your RHD patients?

Respondent:she is 16 making 17

Interviewer: I mean like all the patients who come here

Respondent: That patients who always come here?

Interviewer: Yes

Respondent: Here I think most of them come to 17

Interviewer: 17?

Respondent: I have seen very few of 18 but mostly of 17

Interviewer: Ok, are most of them in school or they have abandoned school because of their illness

Respondent: Most of them are not in school

Interviewer: Ok

Respondent: Most of them are not in school and we try to counsel their parents to let some of them remain in school but because they fear, you find them that they first let them to stay home not until they see that they are fine but those ones who are very ill, they are no longer at school

Interviewer: Ok

Respondent: Yes

Interviewer: Then when you talk to them, are they generally aware of the link between sore throat, acute rheumatic fever and RHD?

Respondent: No, not at all

Interviewer: Not all?

Respondent: Very few are aware but with the bit of sensitization that I have made them actually to come to the hospital, the few are aware but the awareness is not yet so broad, it's a little minimum

Interviewer: So, what sorts of symptoms do they describe when they reach here?

Respondent: Yes when they come here ,ok...some of them, they start telling you that they have done local tonsillectomy and then others even tell you that actually you see that they have brought a child with pains on the joints, fever and they have been treating for malaria but now eventually when they strengthen

Interviewer: Ok, is local tonsillectomy so common around?

Respondent: Very common

Interviewer: Ok, on average, how many children like the percentage of them who have local tonsillectomy?

Respondent: If you get children from 2 years to 6, you pick 10 of them, either they are among them, you might get only 2 or 3 who has not done that, meaning that the majority of our children go the local tonsillectomy

Interviewer: So, do they do it or is it like a form of a treatment option that is acceptable in the community

Respondent: It's a treatment option, very acceptable in our community that even in the hospital now, when you go to the children's ward, you will get that diagnosis called "Gidwon sepsis" meaning that they have done tonsillectomy or tonsillectomy and it has caused sepsis, so they call it "Gidwon sepsis 'It's terrible that even those ones who have not yet done it, when they come to the hospital, they still sneak somewhere and do it, it's that bad

Interviewer: As a health worker, what do you tell this parent who has done that?

Respondent: Oh my God! Sometimes you have to beat both laughs.... But now you can't beat because there is one thing, no mother will do something to a child to kill, and they are doing because they think they are helping their children, so we need to talk to them, we always have to talk to them and we should always have that patience with them, that when we tell them the experience of or what the child will go through later, they will learn not that they will all learn at once but I know time will come that the majority will take it up because they don't do it for harming their children but they think they are helping and yet they are harming, so we have to

accept them as parents and we have to appreciate that they are doing it for the betterment of their children but we have to tell them the better way of doing that

Interviewer: So, do we usually have these talks around?

Respondent: The talks?

Interviewer: About the local tonsillectomy

Respondent: Yes, the unfortunate part of us, most of the nurses we do have children and so when we tell them they say that these people lied to us they do theirs **and** because we have children

Interviewer: laughs, so we also have nurses who are doing local tonsillectomy?

Respondent: Exactly, even those nurse do, so I don't know what we are going to do but I know that eventually sensitisation comes out and awareness is created and still we are not going to rule it out to be done but the percentage should come down at once, and once the percentage comes down, we shall score better just like HIV, before the awareness, it was terrible but now we have the awareness.

Interviewer: I hope that will work for us?

Respondent: It will

Interviewer: Generally, about follow up do these people, really is it good? Is their follow up and adherence to medication good, the patients you see?

Respondent: I think for now we are about 79%, especially for those who come in early stage, those ones who do not come in the early stage, even the fact that they know when they are very sick already or they brought their children when they are very sick, you see even picking up at that time for that child to be well will also take time and so they lose patience and once they lose patience, they assume the treatment is not working so they choose other options, they start to go to the witch doctors, or they go to another hospitals or clinics where they are going to deceive them and then eventually they come back, either with a dying patient or they don't come back anymore, when you follow up, the child is no more

Interviewer: So meaning that those ones with like.....

Respondent: Those ones who come at an early stage are picking up

Interviewer: Ok and they are turning up and they end up adhering?

Respondent: They end up adhering, the ones who come with already the generalised swellings, they have oedema, they tend to take long to recover and so their adherence pattern is also poor, it's poor

Interviewer: So, what sorts of barriers do they commonly state they get to the care they need?

Respondent: Actually....

Interviewer: what the patients tell you

Respondent: Just like I have told you, they still don't believe that ah...when they come at late stage and they get treatment, once they get the first treatment, the second treatment, you know now that gross earning and with the medication, we now have that challenge, **the** drugs they need are many, there is also the pill burden of drugs, you know because the heart drugs are already there for the heart condition, hypertensive condition part of it, maybe they have the swellings, the uretic that should be taken and sometimes really some of these drugs are not in the hospital, they have to buy, normally when you subject them to buy drugs, normally our patients disappear because they are going to the clinics that will provide the drugs whether it's a wrong drug but they have been provided, they don't think about how much they have paid there. knowing that I have come to the hospital and am not paying for consultations but the money I have I can use for buying, they just assume that the clinic is better and so that really affects their adherence, lack of drugs in the hospital is a challenge

Interviewer: Then what issues do they commonly complains about like the care, the challenge they get as patients receiving care?

Respondent: Sometimes patients are many **and** so when they come, they have to take long on the line and the fact that they are taking long on the line, they still try hard and sometimes they feel that they are neglecting them, of course when the critically ill patient come, they still have to leave you and go on the other because we even have few, we have few nurses, there are no specific nurse who are ready to handle specifically them, sometimes they are to wait on the line and others have managed like their coordinators and then also doctors are available to see them and sometimes the doctors are not around and yet they may be having like a complaint and so that is a challenge because they may have to come back and yet the distant is long so that is some of their challenges

Interviewer: And then what about the ones you face as a health worker in managing them?

Respondent: Yes, it's not even far different as a nurse, I would feel that my patient is reviewed by a doctor but now there are situation that my doctor, my very doctor who is supposed to see my patient is very busy because he or she is alone and so he has to run up for emergency and this patient has to wait and sometimes they go without being seen or I have to decide and make a decision and start the patient on treatment or I consult my doctor on phone or else this patient needed to be seen by the doctor, that is one, then two, the drugs, when they go, there are days that even the drugs that are supposed to take like just aspirins is not in the hospital, they are supposed to buy and some of these clients are un able to buy and this could be the reasons why they did local tonsillectomy from home ,they didn't have transport to take them to the nearby health centre or even to buy a drug to treat those inflammation, the sore throat', so therefore they have no choice, they do it because they are willing to do it but as a solution to their problem and then lastly, most of my patients are children and I need to separate them from adults but because the space in lira hospital. is not there for children, even when we admit them in the ward, we admit them amidst the adults and my children's ward where the children's ward are takes them up to about 4 years so you see now 4 up to 16 where I was telling you 17 years, where do I take them, to the medical adult ward which is very bad for my patients

Interviewer: Yes

Respondent: Yes

Interviewer: Ok, I understand and then what sorts of barriers do you perceive that they face in getting the care that they need, what you feel they go through

Respondent: The barriers here are not so many, the barriers I would bring out

Interviewer: Like you are looking at the patients views on your perspectives

Respondent: The barriers here just you know when there are children, they are very innocent, the barrier we get is on those bigger children say from 12,13,14,15,16, most of them believe they are not going to get better with a lot of anxiety being among them, though they complain that their medications pains and because they want to get well at that age, they also come back but there is that anxiety that remains in them that communicates to them that heart condition remains heart condition and they will not get better any time soon and this life sometimes like my daughter, it really created some barriers between me because which word would I use to convince them, convince her that she would get better not until I bounced her to another person for counselling her, so there is that barrier to believe that they will get well soon

Interviewer: So, you feel they are not getting enough counselling?

Respondent: Exactly

Interviewer: Ok, what else are they missing out that they should have gotten, that you feel they should have gotten

Respondent: A part from that counselling is paramount and their medication, I think even proper investigations are a challenge because like I told you, once other things are to be investigated apart from the ones the hospital provides, its needs money and maybe they cannot afford and that is really a big challenge

Interviewer: Ok

Respondent: Yes

Interviewer: Ok, something to do with the local health system, tell me about you administration and the leadership in the district, what do you think they are doing well

Respondent: In the management of RHD?

Interviewer: Yes, general, at the hospital or ministry of health, do you think that they are doing well?

Respondent: I would, they are not

Interviewer: Why?

Respondent: You know there are for ministry of health, I would say this, ministry of health eventually focused on the other conditions, for instance since I have been, since I have up graded my studies, you know global health, what it talks about, people are on maternal child health, people are dwelling on mothers and their babies, the neonates and then what also came in was HIV, that one is also there, so global health is focusing on other things, RHD has never been on the policy and yet me and you has been in lira hospital and you have seen the population of people develop hypertension, people who develop these problems and then they eventually die. Very many people have died because of RHD, all the heart conditions, almost we have, when you dig down to their history, they have these issues and these are the young teenagers, people who are brilliant, people who should have taken us up.so I was seeing that other disease. I would talk about this RHD disease, why not come as a policy, also so that we also do a study in it, so that we can also develop from there and we put its sensitisation so that people are

helped down here because right now in the hospital, when we want investigations for RHD conditions, you will look for this machines and they are not there because they're not catered for in the policy

Interviewer: Ok do you think it's the administration issues or the leadership in the district

Respondent: It's not the leadership from the district, it's right away from the head

Interviewer: Which is? The ministry of health

Respondent: Exactly

Interviewer: So, what can you tell me about the funding of health care in general or on RHD in particular?

Respondent; No, I will talk about the funding of health, **health** facilities you know these funding comes when they are directed to specific issues. There has been no funding that comes to the hospital and they say you can use it with what you want, they come when they are directed on specific programs, I have always sat on meetings, we have always done the budget together but there has never been any funding for RHD

Interviewer: Ok, why is it so, is it because it's not placed in the budget

Respondent; It is not us, it has to run with what the ministry of health is focused on, maybe how it can come out in this hospital, I can come out maybe to take up a research in lira hospital and then we take up a research as lira regional referral, then when we do the research, we write up a proposal and then they can allow to fund us and then we can get money but for the money to be sent from there, right now RHD is not in the policy of health management, not any, there is nothing from me, as a study, they are not even aware that it's there, I think as a major cause of deaths

Interviewer; Ok

Respondent: So, they are not aware and so they cannot send us money that is what I could say, maybe if they are aware of RHD then the money they would pay for RHD is here

Interviewer: So, in which way can we make them aware?

Respondent: We can make them aware by doing a research because we have these patients here in the hospital, we can take up a research, after taking up the research as a hospital, we present our research to them, with the study, we are making, after finishing the study, we

present it to them and then we decide together because we shall let them know what the cause of mortality in the hospital

Interviewer; Ok, what about the health workers, do you think that the numbers of the health workers are enough

Respondent; Of course, the number of the health workers are not enough **because** when you compare the ratio of patient to nurses. I think I would say one nurse is handling over 20 patients, during the time of duty schedules per day and that is too much, it takes of out what I could, how do I say, the quality of services is reduced, we are only doing the quantity

Interviewer; laughs, so how is the waiting time here?

Respondent; Wow! Of course, it's long, very long

Interviewer; What about the quality of care

Respondent; The quality of care, as someone wears off to see 20 patients, the quality of care also reduces as I had told you that the ratio of patient is 1: 20

Interviewer; Quite a big number

Respondent; Yes

Interviewer; And then do we have medications available for these patients?

Respondent; It's on and off, I would say so, not very reliable

Interviewer; Ok, how about the diagnostic, like echo, is it available, readily available for the patients?

Respondent; Yes, for now those ones we have, it's either provided or someone is sponsoring it for them, I see it's still available, I see the hospital itself does not have

Interviewer; Ok, are the services free?

Respondent; Yes, right now they are getting free services

Interviewer; Ok, so tell me about your record system, how is it, is it really working well for you

Respondent; Our records system is not so much very well working for me, as an in-charge, we have a register in an emergency department where we register patients we have seen but I know

when we go for the data entry, I don't see those very patients being captured as in RHD, they are captured as other illnesses

Interviewer: Meaning that they are not captured anywhere

Respondent: They are not captured anywhere as RHD and yet that would also be when we go for, how do I call it, when we go for the annual report presentation, we would also say that there is something that is making deaths or something making children very ill in lira regional referral if it was specifically captured as RHD but now it's captured under other illnesses

Interviewer: So where is the problem. is it at the records department or the way it's captured from the register?

Respondent: No, it's..., the problem is nowhere, I would say so because it's not yet striking, it is not yet been put as an alert or attention to anybody, nobody is aware, yes there is a problem called RHD

Interviewer: Ok, or maybe like in the health information, that management tool

Respondent: It's not even there, it's not in the management tool

Interviewer: So, it can't be recorded

Respondent: It's not in the tool, so it cannot, that is why am saying that no one is aware

Interviewer: But you recorded it in your OPD register

Respondent: Yes, and it's now under other illnesses

Interviewer: Ok, I see, so do we have guidelines and protocols for RHD care?

Respondent: No, we don't have

Interviewer: You don't have?

Respondent: Yes

Interviewer: Ok, we have talked about this but I also want to know like what you think that leadership in the district is doing well. Something at least they have done well?

Respondent: The leadership in the district or hospital?

Interviewer: In the hospital here

Respondent: I think our director has been very positive because when we requested that the children with RHD should be provided with space that they don't come up in the hospital and line up in the hospital to wait for the other OPD line up, he was very positive and he identified the space, he said, he ask in the meeting where can we take this and the people decided, they said we have a room or they can share with the emergency people, it was very positive and we have a specific corner for these children, so that when they come, they come straight and get their treatment, those ones who are coming for review and then they go back, they come get their treatment and then they go back and the nurses in the emergency are aware of them, immediately they present their cards, they know that this one should be handled and she already goes back

Interviewer: Ok, like funding for health care, what have they done well according to you?

Respondent; Concerning RHD?

Interviewer: Yes

Respondent: Paying for staff salary...both laughs

Interviewer; so that is the only thing they have done well

Respondent: By giving us salary and then they have done fairly, poor, fairly, poor, I don't know, the drugs are fairly available

Interviewer: Ok

Respondent: Yes

Interviewer: Ok, what about the health workers, what do you think you are doing well?

Respondent: We are always available, we have always been with them, counselling them, we have shown them love and care, the parents are friendly, they call, communicates, some of us has given them our number, they call to consult and then we tell them what to do, I know that we are doing well

Interviewer: What motivates you to go on working?

Respondent: Personally, what motivates me to work I would not say even anything but it's a passion, I like my work, I just like it and above all I just love to see children or patients recovering so it's just passion in me

Interviewer: Ok, you talked about medication being available for the patients like for a few of them

Respondent: Yes

Interviewer: Do you have BPG readily available

Respondent; BPG....

Interviewer: Benzathine penicillin

Respondent; Benzathine penicillin yes, true

Interviewer: ok, what good has the record department done?

Respondent; Just like I said, our records do very good data, I was in....i went for evaluation of last financial year in kabale, lira was one of the best hospital who presented very well and I think we are doing well, only if they would add on to their records and the data capturing may add RHD, I think that we would strike because in that meeting, there were staffs from ministry of health and they would look at that and say Wow! There is something we are not aware of and that would bring us out, yeah

Interviewer: That is very true. Ok concerning perception of patient outcomes, do you think that they get the care that they need, like surgeries?

Respondent: Most of the parents who are here on treatment really believe that they are getting the care that they need because we are counselling them, we tell them exactly what has caused what they are seeing and the complications that thing brings and then what we are going to do. When you talk to them they understand but sometimes when it now comes to the need for surgeries, you find that our hands are tied up, we need to start talking about Mulago, when they hear about Mulago, what rings to their head is money and then of course we have very few, we have very few patients who would need surgeries but still the few we have when you tell them that it's not very good, they start fearing that they are going to pay

Interviewer: Ok, any patient's safety and quality of care concern

Respondent: Patients safety yes, we keep our records, we don't stigmatise them, they are free with us, we tell them this is not a disease to be stigmatised on and it's a disease that has come, they adhere very fast and because they adhere very fast, I don't see that there is any big problem

Interviewer: Ok have we had any preventable deaths in the hospital

Respondent; Preventable deaths

Interviewer: Yes, like how would it come about?

Respondent: What I can say, the preventable deaths, when we have patients who come, who are referred are not specifically RHD, sometimes our patients are referred from the nearby health centres when they are really having complications just like I told you that ah...maternal health care is still a very big issue, you get a mother with APH coming in when ,when they come in sometimes they want to go to the theatre and when you ask them, their Anaesthetic drugs is not there, you feel something should have been done and the drugs should have been there, by the time you get the drugs, someone goes to cardiac but now that is very late surgery and you see someone dying, you get it

Interviewer: Yes

Respondent: Those kind of deaths would have been prevented because if they were referred and immediately entered the theatre and surgery is done, that would be good for us, other things are like right now we don't carry out heart surgery and if there is any problem that needs urgent heart surgery, and we are unable to do that

Interviewer: Is it because of the equipment or the....

Respondent; It's the specialist, the staffs, the specialised staffs are not there for that, equipment are not there, we are not ready to handle some of the emergencies and so what will happen, deaths will occur

Interviewer; Ok

Respondent: Yes

Interviewer: That's really very sad. Do you think that patients are dying in the community without presenting to the hospital for care?

Respondent: Very true

Interviewer: What do you think is causing this?

Respondent: We also have what is called ignorance and we also have what is called traditional beliefs, cultural beliefs, there are still people who believe they are being charmed and because the patient does not have a voice they die. We have seen very important people who would not accept to die but because now he or she was in a situation where he has no strength for himself

to run to the hospital, end up dying at the witch doctor's place and then eventually the relatives come and tell you, you know he was a teacher and so we wanted this not to happen and when you start asking why didn't you bring the patient to the hospital, you know we were now trying but we had taken him for prayers somewhere and yet you know that person would not accept to die there but because he was helpless, they carry you and take you anywhere, so I believe they are still there

Interviewer: Ok, so in your opinion, what are the most important things ministry of health should do to improve outcomes

Respondent: One, ministry of health should change the structure, the structure of health management right away from personnel to the housing must change, for instance, lira regional referral hospital was built in around 17 or 15 something, am not aware about that the very structure are there, where there are the ones we are still using mostly not of late that the new ones are coming in but in the staffing, structures is like 'oba' for which year, the staffing structure has not changed and yet the population of Uganda is rising, the more the population rises, the more the population of the hospital will go up with very new diseases that are coming in and so the staffing structures should also go up to compensate the weight of the patient in the hospital. I will talk about it not so much talk about the facilitation because if we are not overwhelmed, someone will not also think of so much being facilitated, someone will work at a strict time, go out and do something else but because patients are very many and we are few, we tend to take longer time and by the time you are going home, you cannot do any other business to supplement your salary and so we ask for money which money is not going to help us. We need more staffs, so we work and get less tired to renew our brain to do other things that supplement the little salary that the government gives us to make us move on and indeed health will not breakdown anywhere

Interviewer: Ok, what else do you think the ministry of health could do?

Respondent: The ministry of health should also know that as the population grows, even the supplies of medication should also increase so that we can manage these patients and then follow up. ministry of health should learn to follow up, there are people put there are, people who come for follow up and see what is happening, they should come and interact with the staffs, there are people who should come and go to the a data base for us in emergency and go and go to the wards and see your records and see every ward with its report because for us in emergency, we have every reported, our report tell us, tells people, how many people we get

with RHD and how many patients do we get, then you get that there is also RHD and I tell you on this financial year, we added like 100,one financial year, in these, how many have died, we then follow up.so if there was that follow up, they would really capture these things earlier before us. But now I see as if follow up comes and ends up in the office and they are not aware.

Interviewer: Ok, thank you so much unless you have something else to add on

Respondent: Something else to add on, I just feel like I could request for the ministry of health if possible to start training a specialised nurses, we have doctors who are specialised and we have nurses who are willing to specialise as well so that where the doctor is not there, this specialised nurse at least have something in common they share in the, management of specific patients, ok for instance like in Mulago, we have nurses who have done nursing and now they are working at the heart institute, when the doctor is not there, she knows what to do but here in lira regional referral, it's not there. We are having knowledge we got from school. What about the day's patients will change position and the physician is not around, what will I do, I will have to wait or I mess up the patient or I refer the patient but before I refer the patient, I needed to have done something. So I will just request for training for the capable nurses and then willing nurses with compassion to come back and help the community, that is all I could say and yes, that is all I would say and really thank you for the people who introduced RHD management in this hospital, they are doing a good job

Interviewer: Ok, thank you so much for giving me your time and to participate and I know your views will really help us in improving care for the patients with RHD

Respondent: Thank you.

0241

Participant ID	HW 009 - Lira
Age	■
Date	7th /Jan/2019
Venue	LRRH
Interviewer	

So briefly, We are conducting this to see how best we can help patients with rheumatic heart disease, yes so thank you for being part of this interview, so can you tell me about yourself.

Interviewer: How old are you?

Respondent: ■

Interviewer: What is your qualifications?

Respondent: My qualification.....I am a medical doctor, ■

Interviewer: From which university?

Respondent: Where I work?

Interviewer: Yes

Respondent: I work in paediatric ward

Interviewer: Ok

Respondent: I have been practicing in the paediatric ward for ■

Interviewer: ■ year?

Respondent: yes

Interviewer: Ok.so where did you qualify from?

Respondent: Pardon?

Interviewer: Where did you qualify from?

Respondent: I qualified from ■

Interviewer: Ok

Respondent: Yes

Interviewer: And you have worked here for [REDACTED]?

Respondent: I [REDACTED]

Interviewer: ok

Respondent: [REDACTED]
[REDACTED]
[REDACTED]

Interviewer: [REDACTED]

Respondent: [REDACTED]
[REDACTED]

Interviewer: ok

Respondent: Paediatric ward I was posted [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Interviewer: [REDACTED]

Respondent: [REDACTED]
[REDACTED]

Interviewer: Ok, so which patients do you, age group do you see?

Respondent: The what?

Interviewer: Age group of the children

Respondent: Age group of the children like the paediatrics where I stay, where I work

Interviewer: Yes

Respondent: We always admit between 0 -5 years

Interviewer: 0 -5 years?

Respondent: Yes, 0 -5 years, if they are beyond 5 years, then they are always sent to medicine ward but here we admit those below, let me say 0 -5 years

Interviewer: 0 – 5 years?

Respondent: Yes

Interviewer: What is their common illnesses you meet there? The common illness you meet

Respondent: The common cases

Interviewer yes

respondent: The common cases we are like meeting on the ward we are like meeting acute water diarrhoea and we also meet respiratory tract infections, both lower and upper where by you see pneumonia, bronchi pneumonia and then we commonly see malaria, malaria is common. Many of the children are having malaria and septicaemia, you know septicaemia comes maybe as a result of another blood infection, even pneumonia can make your child have septicaemia, even everything can have septicaemia, so we always see septicaemia because when we do their CBC, you white cells are increased, whatever those things are high, so we end up saying septicaemia but while there is another underlying cause for that septicaemia.so those are the common illnesses, diarrheal diseases, acute watery diarrhoea, we like seeing malaria, we see pneumonias and then once in a while we see unique cases for example we have ever, last week we had a child with measles in the ward. We had 4, they were 4 and then we like seeing also heart condition's once in a while and then we always see them, we like sending them for cardiac echo, they always do it and then chest x-rays to make us see how the heart is and then we also see other abnormal, most un known common conditions eh...for example like paralytic ileus, the child's intestines have stopped moving, that is partial intestinal obstruction, we also see them especially with these very new born, they like coming with paralytic ileus, most cases and then neonatal...early on set. Neonatal sepsis ,sepsis, for children who are like 0 28 days, they like giving them diagnosis like that because they have fever, they are refusing to breast feed ,crying ,so we say early onset neonatal septicaemia, sepsis, that is the most common things we see although they are unique ones. Kidney problems also can come in, heart conditions can come in, just like that ,even the liver sometimes they may have hepatitis, once in a while ,not so common

Interviewer: Ok that is great to hear. About your training, have you received any training at your school on RHD? Rheumatic heart disease?

Respondent: Specific training?

Interviewer: Yes

Respondent: I haven't had any specific training a part from the training which I got when I was doing my medicine and during that time I used to practice medicine at diploma level. We used to meet such cases of rheumatic heart disease, hematic fever...eh, once in a while but specific training on rheumatic fever, rheumatic heart disease, I haven't had. A part from last week, there was a CME about rheumatic heart disease and rheumatic fever but I haven't had a special training

Interviewer: So no any training since graduation?

Respondent: pardon'

Interviewer: so it means you have never received any training after graduation?

Respondent: The training of?

Interviewer: Rheumatic heart disease

Respondent: I haven't ok, I haven't. I haven't of course maybe because the program did not come here or it came and I did not know.eh...you know sometimes programs come then they might not even inform you, you are here on the ward and people are doing other things you don't know, that may happen but so I have not had because I haven't been called because If I am to be called, they have to come to me and say, you are selected for this training, can you , could you please come or give me a letter, they have not

Interviewer: Ok, so how many patients of RHD do you always see, let's say in a week?

Respondent: I have ever seen 2, 2 sometime last yeah, we had a child in the ward and we referred to this people and rheumatic fever was confirmed because the child had joint ache, Somme un usual rash, skin rash and fevers for sometimes and we referred here and the child was checked and I think was confirmed of rheumatic, then there was also another one, that one was a girl, I have ever seen a girl child. The girl was around 8-8-9 years, a big girl 8-9 years, then I have also seen a child of a round 5 – 6 years, that was a boy, that one also came with the same presentation, swelling of the joints, on and off and some fevers that were un usual, so when we re-referred her, they checked and they confirmed and I think they are still under care with these people

Interviewer: Ok

Respondent: They are still under care still because they used to come for reviews, those are the only two I have seen

Interviewer: In almost a whole year?

Respondent: Yes, I think the whole year when I was here, those are the only ones I saw. That this one has rheumatic fever, could be that they are there but maybe they haven't complained, I don't know thematic fever may come as result of a complication of something, for example if somebody had maybe a sore throat can end up in thematic fever, just like that, maybe ...maybe there is always, they come like sore throat, then it goes away yet it may be thematic fever, that's why we maybe don't detect and the problem here is maybe the investigation system of it. The hospital does not have good investigation system, yeah, that is our major problem

Interviewer: So the ones you saw with RHD, were they inpatients or out patients?

Respondent: This one, this one was inpatients at first, but when we transferred to these people, then we discharged from the ward, they became outpatients. They have been coming from home to these people for review, they would come and they were on treatment

Interviewer: Ok, what is your understanding Of what causes RHD?

Respondent: what causes it?

Interviewer: Yes

Respondent: Rheumatic heart disease...I think it may come as a result of the rheumatic fever that wasn't properly handled, I could say maybe a complication that develop rheumatic heart disease. Also I may think its bacterial infection for example if somebody had a sore throat and mostly the common bacteria causing sore throat maybe streptococcus infection not well treated with antibiotics, it may end up to the heart then it cause rheumatic heart disease

Interviewer: Ok

Respondent: Yes

Interviewer: Ok, are you aware of the link between sore throat and rheumatic heart disease, you have just told me about it

Respondent: About?

Interviewer: The link between sore throat and RHD

Respondent: And rheumatic fever

Interviewer: Yes

Respondent: Yes, I have already told you, it may be like somebody has rheumatic fever not well managed. Complications rheumatic heart disease, it ends up, it ends up in the heart, that's why we must manage these rheumatic fevers properly and even sore throat, and you give strong antibiotics that may kill those bacteria so that it doesn't end up in the heart

Interviewer: Ok, so what were you told that can be done to prevent rheumatic heart disease?

Respondent: I think I was told anything but that I think is maybe the public or community could be sensitised about the problem of RHD, sensitisation. And in the sensitisation, you could put there ...the first of all the disease itself, you should explain it to the people how it comes and of course the signs and symptoms that may lead to rheumatic heart fever, if somebody has seen the child is having swelling in the joints and the joint pains, then fever, abnormal skin rash, may come for screening, that is what we should do. I think I just think, although I have not been told but I think that is what must be done. We should educate the public or the community about the disease, we sensitise them and then they see the child like that ,they bring for us for screening and get treatment so that we may suppress those bacteria, those bacteria not to go into RHD ,I think so that is what we can do

Interviewer: Ok, what about the treatment option, what were you told were the treatment option for RHD?

Respondent: Treatment options?

Interviewer: Yes

Respondent: I would think of the penicillin's

Interviewer: Ok

Respondent: penicillin's like, IV ampicillin or IV benzyl penicillin, penicillin because streptococcus I think responds well to penicillin

Interviewer: Which treatment option do you know about?

Respondent: Treatment options, maybe, maybe if there is no penicillin's, you may give ceftriaxone

Interviewer: What is your understanding of the long term prognosis of RHD?

respondent; About the prognosis, yes the prognosis would be good if it's early detected, if it's detected early for example if a child has rheumatic fever only and you detect it and give good care for it or if a child has a sore throat and you give that child good anti-biotics for the sore throat, I think the prognosis maybe good but of course if it has gone to RHD and whatever maybe the prognosis can also be poor but if you manage it in its early stage for example like a sore throat has started then you give good antibiotics, it will suppress it and there it will not go into RHD

Interviewer: Ok

Respondent: Yes

Interviewer: I understand, so you talked about meeting 2 patients, could you talk about the last patient like the last patient with RHD, just briefly summarise what you saw in this patient

Respondent: ok, the last one?

Interviewer: yes, the one you said you saw

Respondent: The last one, the boy was around 5-6 years, he came with history of joint aches, the joints were paining, all the large joints. This one here, the elbow, the knee joint, the ankle joint, they were paining like for 1 week, then in the 2nd week, this boy, this was paining and the boy was having fevers, the fever were running on and off while the joints were paining for 1 week. In the middle there running to the 2nd week, he began some rashes, rashes were in the face even on the trunk, that one was like for around 2-3 days, then they came to the hospital, when they came to the hospital, for us we managed, we first of all managed with anti-biotics but then we decided to take him for screening because his presentation were unusual, so we treated that pain of the joints and whatever. Symptomatically, we were managing the child then we sent to those people and they confirmed him to be having rheumatic fever, those ones at the tent, so from there these people took over this patient, we discharged the patient from the ward and then they took the patient over, I think from there, it was an outpatient. It was up to around some times in august, this year they were still coming for review, I don't know whether they still come, they were coming for review

Interviewer: Ok

Respondent: Yes

Interviewer: So what is the average age of your RHD patients?

Respondent: The what?

Interviewer: Average age group of RHD patients, rheumatic fevers or RHD

Respondent: RHD? I think the average age could be between 5 -10 years, some may even go above 10 years

Interviewer: Are most of them in school or out of school?

Respondent: They are in school

Interviewer: Most of them are in school

Respondent: Most of them are in school

Interviewer: Ok when you talk to them .are they aware of the link between sore throat and RHD, the patients or their care takers are they aware?

Respondent: They are not aware, they are not aware they don't know, they don't understand that if somebody gets a sore throat ,if not well managed, it may give another complications, they are not, they are not aware of that, they are not aware that is why I was saying that the public should be made aware of how that thing comes, the causes and even the presentation and signs and symptoms so that they may understand when they see somebody like that or a child ,they can be able to bring to the hospital immediately

Interviewer: Ok, so what sorts of symptoms do they usually describe to you when they come?

Respondent: what?

Interviewer: The symptoms, what symptoms do they describe

Respondent: The symptoms

Interviewer: Yes

Respondent: For them they describe that the child was having fevers that were running on and off, then the joints were painning, that the child could cry in the night, that there is joint pains and then some of them may have inability to use that limb properly. And when the child has started inability of moving and using the affected part that is when they can realise and they start bringing to the hospital because now the child is not moving

Interviewer: How is their follow up, do you think it is good? Do they adhere to their medication?

Respondent: Adherence to medication, of course if the disease is acute they can adhere to medication but of course when it comes to the time for coming back for reviewing them, some of them don't come

Interviewer: Why do you think some of them don't come n?

Respondent: I don't know whether they have not understood the explanation of the review or what, but some of the defaults, they default so emphasis could also be made on that point of coming for review after the treatment when it is still acute. They like coming because they want the symptoms to go, the moment the symptoms have disappeared and the child is now running, playing around, they may forget

Interviewer: What sorts of barriers do they commonly state to getting the care they need?

Respondent: The what?

Interviewer: Barriers or challenges that they face in getting the care that they need

Respondent: Barriers?

Interviewer: Yes

Respondent: Barriers to what?

Interviewer: Getting the care that they need

Respondent: Maybe the barriers they may get for the care they need

Interviewer: yes

Respondent: Hospital barriers or barrier at home

Interviewer: No, either way

Respondent: Either way. ok let me start from back home where they are coming from, maybe these patients are living far away from the hospital, then they may complain of the transport because if somebody is living in the village for example some villages are very far from here, like maybe 40kms or 50 kms, yeah, some even 90 kms from the centre of this town from this regional hospital, then transport will be a problem. Second barrier could be poverty, the family may be poor so that they cannot afford to also pay for the transport, and those are the barriers

at home. And the also a cultural beliefs, cultural beliefs because in Lango ,when there is a sore throat people like going to the traditional healers to check on the throat and see if there is a pus there, let us take to the traditional healer to remove ,in fact they even cut off the tonsils sometimes

Interviewer: That is very sad

Respondent: Haven't you ever heard of that?

Interviewer: Yes of course

Respondent: They are very common. Local tonsillectomy. and that is what we always see on the wards, local tonsillectomy with septicaemia because already sepsis could have set in because of the local thing done and the septic techniques used and whatever, so cultural beliefs also, cultural beliefs, people believe more in those traditional healer than medical treatment especially in the villages, you know most our patients here, they're not these ones who live around, they are people who come from far ,these people who live around the town I think because of the care, even the families are not so poor and whatever so they don't like getting sick like those ones far away, so it is those ones there and they have cultural beliefs there, then in the hospital here the barriers we have first of all could maybe lack of personnel also personnel for example that speciality of rheumatic fever and RHD is a special thing.so personnel thing for care may not be available although there are medical personnel you see even me you see, I am telling you I haven't had a training , you may be there but you may be having what ,little knowledge. For me I have the knowledge from school about RHD but a special training makes it very difficult for even other personnel like nurses, clinical officers even medical doctors, so personnel could be a barrier. Secondly, in the hospital here also the investigation methods we used, our laboratory is almost dead, I am telling you that one maybe if I am talking something sensitive...

Interviewer; , no its okay, everything is confidential

Respondent: Yes, the lab here is so, so dead, these people here don't even o mere CBC

Interviewer: Why? They don't have the reagent or?

Respondent: Even if the reagents are there, for me I think it is just personnel attitude

Interviewer; Ok, like they don't want to do the test

Respondent: They don't want because I have worked with them for long, they don't, when you send the patient there for CBC, what is the reason for not doing? We are not doing, they have not even told you. Just go to the clinic, the patient will go the clinic

Interviewer: Even if the reagents are there or not there?

Respondent: Of course sometimes it might not be there, that is true, it might not be there but there at times even when it's there and they don'tI have ever noticed one time I wasn't feeling well. I wanted to do a CBC, that time I wasn't in paed, I was working in LIDC, so I went to see a fellow w doctor who decided to do a CBC for me, so I went to the lab, the previous day I had sent a patient there to the lab for CBC, even that morning, the patient was turned down.so when I went there myself that I was going to do, they did it for me, now I was questioning, I said, why do they ,why do they minimise CBC and yet I sent the patient and they were sending away, that was my question. That is what made me come with a conclusion that they have the reagents, sometimes but they don't want to do for the patients

Interviewer: Ok it seems, like they want money

Respondent: That is the thing, that is the reason because there is no way you can do for the staff and the patient comes from out and you say no and yet they're the ones who really needs that care.eh..., so the investigation here is a problem. I work in the ward there, all CBCs I send out and the patients has to pull 15.000 for doing CBC, if you're doing liver function test, kidney test it, may be more than, the patient may pay like 75000 or even 100,000/= which is too much money. A part from the RDTs which we do on the ward, not even in the lab but on the ward

Interviewer: You gave the strips

Respondent: That we are given the strips, so that one we do on the ward but it needs the lab so they even don't, they rarely do it, so the lab is a problem here. I think those are the barriers, then another barrier could also be lack of drugs, sometimes you may prescribe a drug for the patient and then it's not in the hospital but if it's there they always give, but there are at times, we always have shortages and the drugs are not there so the patients has to buy, so it may become a barrier

Interviewer: Ok, what about what you face as a health worker

Respondent: The what?

Interviewer: The ones you face, the barriers you face in taking care of them?

Respondent: I need training, I need to be trained

Interviewer: Do you feel you lack training?

Respondent: I feel I should be trained about that rheumatic fevers especially, so that I can take care of the patient that is my barrier

Interviewer: So like you feel you are not confident enough to take care of these patients?

Respondent: pardon?

Interviewer: You feel you are not confident enough to take care of these patients because you lack training

Respondent: No I can take care of them, I can be confident and take care of them but I need the knowledge yeah, I need the knowledge

Interviewer: Ok

Respondent: I need the knowledge

Interviewer: What other barriers do you perceive the patients face, what you think, what you feel they face

Respondent: The challenges, maybe I could for example when they come to the hospital and they be bouncing, sometimes they may bounce because if they come and they don't get the personnel to take care of them, that one is bouncing, that could also be a barrier to them. and also when they come and there is no drugs given, they may be discouraged that when we go to the hospital, we come without drugs, what is the use of going there, let me just go to the clinic and buy, that could be a barrier. eh... I think those are all.

Interviewer: Ok, so about the administration and the leadership in the district, what do you think they are not doing well?

Respondent: The what?

Interviewer: Leadership or the administration?

Respondent: Administration I don't know what I can say about them, I don't know actually, in fact that one, it seems I cannot comment, I cannot comment

Interviewer: Ok, do you think they are doing well? What about the funding for the health care?

Respondent: The what? The health care

Interviewer: Yes

Respondent: Of course the administration, I can see that maybe they also try their level best to see that maybe for example like the lab is well equipped, or the part of the administration. I think they see it that all the things are in place and then also for the drugs that may be lacking, they also try their level best to make the drugs available most of the time

Interviewer: Ok.so do you think all those drugs available like those of.....

Respondent: I don't know what they do ,what they think about training of then staff, I don't know ether they have ever trained other staffs on RHD or not, so training they should also be able to think of training but I don't know whether they do it

Respondent: Yes

Interviewer: So what of the medications like for benzathine, anti-failure regimen, do you think they are readily available?

Respondent: Medication for heart failure?

Interviewer: Heart failure yes

Respondent: Yes, they are there, they are always available. Like today I was in the pharmacy and I saw that they have cardiac aspirins, they have there is this drug called astovast

Interviewer: Atorvastatin?

Respondent: Yes

Interviewer: ok

Respondent: I saw they have in stock now but there are times when you go to the pharmacy, you find when these drugs are not also in stock, I think that happens in all government hospitals

Interviewer: lack of drugs

Respondent: Yes but now they are in stock right now

Interviewer: Ok, do you think that you have enough health workers

Respondent: Here?

Interviewer: Yes

Respondent: We may not even be having enough, we may not

Interviewer: what is the average waiting time, for example you were talking.

Respondent: The what?

Interviewer: You were giving me an example

Respondent: The what?

Interviewer: You were giving me an example

Respondent: For example the ward where I work, these days I sometimes work with only one nurse during day time and yet you know during day time there are many things to be done in the ward. When the doctor is there doing the ward round, one is recording, eh..., the number recording whatever you are write and then another preparing for treating, another person preparing to give IV drip ,another person maybe to looking for the lines but these days I have only one nurse, one nurse like this during day. And then in the evening also one comes, then at night one comes, then another off duty,

Interviewer: It seems like there is as shortage of staffs

Respondent: Yes, there is shortage of staffs because at first, I used to have 2 nurses

Interviewer: On each duty?

Respondent: Yes on duty, sometimes even 3, but these days I don't see , there's only one

Interviewer: Have they reduced the number or they have been shifted somewhere else?

Respondent: I think they were shifted somewhere else but they never replaced them because they removed 4 nurses from my ward and they took to the other units but they were given only either 2 nurses, 2 new ones, I think some have go back to school, I don't know what has happened or some have been transferred and they never replaced them

Interviewer: So what is the average waiting time for patients?

Respondent: waiting time for?

Interviewer: For patients

Respondent: From patients

Interviewer: Yes

Respondent: In my ward

Interviewer: Yes

Respondent: For them to be seen

Interviewer: Yes

Respondent: No they don't take time because we are 2 medical officers, so we always see them faster, we review them very fast, even those ones coming just for admission, we review them and we write their treatment and they are given, they wait so long

Interviewer: Ok

Respondent: They don't wait for so long, that is in my ward but in the other ward, and I don't know what is happening

Interviewer: Ok, how would you rate the quality of care in your ward?

Respondent: In my ward?

Interviewer: Yes

Respondent: The quality of care is good, I can say it's good because I can see when I prescribe something, those nurses even if it is only one they endeavour to make sure that each patient has got whatever I have ordered, even this picking up of samples and doing investigations, they also do, they make sure that they do it, so I can see they try, it I good.it is good in my ward but in the other wards I don't know

Interviewer: Ok, as a health worker, what motivate you?

Respondent: ...motivation

Interviewer: Motivation?

Respondent: I don't see but for me if I see a patient and the patient has recovered, that is my motivation

Interviewer: Ok, that makes you to work on

Respondent: More patients, that is my motivation, but other motivations I don't see, I don't think of them ...but if I have treated patients, I have received them well, the mother is comfortable, the child is improving, that is my motivation, that is what I think as a health

worker. I get motivated as the patient is getting well because if you are a doctor on the ward and every morning you come and the patient is dead, every morning they are reporting deaths, even in your bed, there you read death,death,death,4 -5 deaths in one day ,then it means you are doing nothing. But for me when I come I n the morning, I read the report, no deaths, no what, the patients are recovering, I am happy, I am motivated

Interviewer: Ok, that is nice

Interviewer: Ok, let's talk about the medical records, do you think it's doing well

Respondent: The what?

Interviewer: The medical records?

Respondent: Medical....?

Interviewer: Records like your record departments

Respondent: Medical request

Interviewer: Records

Respondent: Records?

Interviewer: Yes

Respondent: medical records I don't know what they do, I have never tried to be close to that department, I don't know whether they are keeping their records well or not because I have never tried to visit, eh to investigate or to go there and find out what they do

Interviewer: Ok, but do have like registers in patients registers on your ward?

Respondent: In patients register on my ward is up to date I think, because every patient is always registered and every patient entering the ward we have a big register they always register them there. Even registration for RDTs, BT, the ones that have had hard all have their books and they are recorded

Interviewer: Ok

Respondent: If you order BT, it is recorded, if you order RDT, it is recorded plus all the results and the particulars of the patients, I think the records in my ward may be better, eh..., its better, its good

Interviewer: So do they record the diagnosis of every patient?

Respondent: What?

Interviewer: Do they record diagnosis of every patient?

Respondent: They do what?

Interviewer: Do they record diagnosis?

Respondent: Yes, they record

Interviewer: Including like ARF or RHD?

Respondent: They do but one sometimes may be the nurses, maybe they don't record, sometimes some of them not record

Interviewer: So how best do you think we can improve the records system?

Respondent: Records system?

Interviewer: Yes

Respondent: Like in the wards, first of all if you want to improve such a thing, you need to call people, you need to call a meeting and then then you address the problem to the staff and then they will see how to make it better. I think that is what we can do ,we should call a meeting, then make an analysis of the records and see ,are they doing it properly, then we tell, them to improve on them, I think that would be better

Interviewer: Ok, and then do you like have a guidelines and protocols of RHD care

Respondent: Protocols?

Interviewer: Yes

Respondent: On the ward?

Interviewer: Yes

Respondent: No we don't have

Interviewer: Ok, so what do you think the administration can do like to improve on, let's say funding in the health care?

Respondent: To improve about.

Interviewer: Funding

Respondent: Funding?

Interviewer: Of health care

Respondent: Funding of?

Interviewer: particularly on RHD

Respondent: Funding, of course funding should be increased, not only funding of course funding is a big title but there are sub groups down there. Funding s good it can be done but it can be improved but when they are funding, they should consider their training and also the protocols that you are talking about. I think it must be distributed to every ward so that everybody is there to see ,eh...,to see because I have seen many ,many things for example the management of pneumonia and whatever ,I have seen the things on the wall, even diarrheal diseases, diarrhoea and rehydration, you see the charts on the On the wall, so I think that can also be done for rheumatic fever and RHD, so that could all the funding because all those things will need money..., that is why I said funding Is a big but under funding there are small ,small things that can be done

Interviewer: What about for the health workers?

Respondent: The what?

Interviewer: Health workers

Respondent: Health workers?

Interviewer: What can be done to make them better?

Respondent: Health workers, for me I was thinking of making them have a training, if possible you can even do a mass training, a mass training for every health worker, that would mean either through workshop, work shop mainly. You can organise and then people go on going like one by one. You don't go all at the same time because if you go all, work will be at stand still, you pick some, you train for this time, you pick some ,you train, just like that and also I think the health workers also they may ,the health worker themselves ,the number may be increased somehow, eh they should increase for example like the nursing department, even medical officers for example if you are now caring for the RHD as special thing, when we need a medical officer, he sits there at the rheumatic fever tent ,yeah ,here in the tent, I don't think

there is a medical officer there. That place would be having good, if it was a good setting, it could be having a medical officer in that team because I can see people who are in that team, yeah because I can see people who are in that team the other cadres of trainers, training, they are not medical doctors, for me I think it would be good also to put there one medical officer

Interviewer: Ok

Respondent: one or two at least two o that they can be alternating, you know, you can't be on duty all the time, this one is on, this one I off, just like that and so the health workers ,government should plan to employ ,either employ more health workers to fill that gap of rheumatic clinic because they will ,I know this hospital is going to have a clinic for RHD one time, a bigger one, so they should plan for that, eh...,they should plan for that so that they put medical officers, put there all cadres of staffs ,eh...,so that they can be able to manage the patients properly

Interviewer: Ok.so generally do you think they are getting the care that they need?

Respondent: The what?

Interviewer: The RHD patients

Respondent: RHD?

Interviewer: Yes

Respondent: I think they could be getting the care that they need

Interviewer: Especially surgery

Respondent; surgery?

Interviewer: Yes

Respondent; No surgery, not here

Interviewer; Why?

Respondent: I don't think they do surgery here for that

Interviewer: Is it because they don't have the equipment

Respondent: May be w don't have a surgeon...

Interviewer: Ok

Respondent: We don't have a surgeon here, that is why I was telling you that personnel, personnel are important in that management of rheumatic fevers, .RHD because is it a speciality, so it needs it to have its own team, ideally even there could be a surgeon working with them, specialised in that, not just a general surgeon because a general surgeon may not do it, it needs a special one

Interviewer: Do you have any patient safety and quality of care concerns?

Respondent; The what?

Interviewer: Patient's safety and quality of care concerns

Respondent: Patient's safety?

Interviewer: Yes

Respondent: Yes of course, like am now talking in my capacity, when we take care of these patients, we make sure they are safe, we make sure that business of cross infection, therefore we may be protecting ourselves with the gloves and we use only one for one patient. I don't put gloves then touch this patient, then put on it again, touch the other one, no each patient you use a different gloves.

Interviewer; so you feel they are protected, there is nothing you are concerned about like

Respondent: About?

Interviewer: Their safety of care

Respondent; About?

Interviewer: Any concerns on their quality of care

Respondent; The patients?

Interviewer: Yes

Respondent: They may be having concerns of course, they don't express it you know, eh but they may be having their concerns also but they may not express it to us also

Interviewer: Why?

Respondent: I don't know...

Interviewer: Is it because the fear interacting with you

Respondent: I don't know why they don't ,it could be sometimes also its just out of fear, they feel these are medical personnel we cannot attack then, what ,what ,eh they don't speak up but they also have their issues, I am sure if you are to ask one of them, will talk for you, will talk for you the issues they have, they have issues but they have failed to express to us, they don't express because of fear, I know fear because most of them they don't speak while they are on ward but when they go outside there and you sit like you are not a medical personnel, you will hear what they are talking..., you will hear what they are talking but when they with you here they will not talk anything, they will pretend that they are comfortable

Interviewer: Ok

Respondent: Yes

Interviewer: So during your time, are there any preventable deaths that happen in the hospital?

Respondent: Preventable deaths?

Interviewer: Yes

Respondent: preventable deaths like in my department, in my department, in my department ,it has not so happened because you know paed how it is, you know paed is always a very specific thing because you know paed patient will either come when he is very pale anaemic and that one you will do x-matching properly, group and bring blood and put already, so the patient will be safe from death because if you don't do that, the patient will just die, in fact one day a patient was referred from HCIII, this patient on examination from there was paper white, so this people I don't know, either they delayed nor what transport the patient, on reaching the ward, the mother, midwife from there was the one carrying the child, I was thinking that maybe she was an attendant, then I asked her where is the mother, then she said, this is the mother, then I asked her, you give the kid to the mother because here I want to talk to the mother, I don't want to talk to you if you are an attendant, so she gave the kid to the mother, the mother sat, on examination, the baby is dead

Interviewer: What!

Respondent: ... The kid died, even I think as she was coming, and she brought a dead body, the kid died and of paper white, a baby of 6 months

Interviewer: What!

Respondent: Paper white, paper white, but that one died even before ,I think as they were entering the ward, the kid was already dead, even she told me that bushel felt it but she wanted me to confirm

Interviewer; so that was due to delay

Respondent; Yes delay, that was delay but if they had reached the ward early, that kid would have survived because for us in the ward there we have stand by staff that always receives those patients with less blood, they do, they do grouping and x-matching straight away, they put the blood. Preventable deaths could also be occurring in other departments

Interviewer: What would be the reason?

Respondent: Other departments for example Obs and Gyn, I think preventable deaths may occur there ,I just think because thee mothers they may come for example a mother with a raptured uterus, so that mother arrives, it needs you to be so fast and here in the hospital, what delays people sometimes, sometimes the mother has arrived you are still calling laboratory, you know what I told you about the lab, they are even not there, whatever you delay in the grouping and x-matching because you can't put a patient on ward with what without having blood and without you doing blood grouping, eh, so you see, that is an emergency which needs everybody to b standby which is not possible in this hospital, here in other wards am sure, that is the preventable deaths I know because the mother was, if the people were standby straight away, grouping and X-matching, takes like only 5 minutes, you are in the theatre, you open the mother, see the uterus or whatever, you rescue the mother or the baby and then you close the uterus but I don't think it happens here, here it takes a process, it might take you one hour to take the patient to the theatre just because you are calling the lab person, he is nit around or he is still somewhere and is not even willing to come ,such things

Interviewer: So there are a lot of delays?

Respondent: There are a lot of delays, delays, delays in the hospital and I don't think only here, all the government hospitals, even Mulago

Interviewer: So why do you think it happens for government hospitals

Respondent: Pardon?

Interviewer: Why do you think it happens from government hospitals?

Respondent: It's because they are not so motivated, government you know the problem, it has ever been like that people are as if they are not motivated, the workers are not motivated, the worse thing with government is corruption, corruption so it makes them not to motivate the workers

Interviewer: So people are not motivated?

Respondent; You remember the other time when we had a strike, how things were, discussing about payment of the health workers almost took so long for them to come to a conclusion and they just did it by force, I think to increase the salary but they could have not even increased, so the problem is like that. It's in I think all government hospitals and you know people, you know a person can get used to a habit, people are used to that habit that you know government ha ,ha everybody ha-ha it's just a habit it's a habit, You see I trained from KIU and also did internship from KIU teaching hospital. There is no delaying, things are done on time, duties are done or covered on time, everybody is on duty, if you are on duty, you are duty.no saying eh...that was people were strict and everybody does what is needed, if not, you don't get the money, they even cut your salary for that but here you people are just, people are just, you know it's the nature of the government and it may take people time to correct that

Interviewer: I hope they correct it really

Respondent: They may correct but not even if they correct, they slip away just like that, they will correct it slowly, slowly ,slowly and you know now days things have been commercialised ,commercialisation of health. Let me say commercialisation of everything, so a person may just think of money, it's very hard and once they have even commercialised a hospital, a person can open his own hospital

Interviewer: Don't you think it can happen in Uganda?

Respondent: Of course, like schools A person can open his own schools, a person can open his own hospital, you see, so it has affected, it affects us.it can affect the health system also if the commercialisation process was not done, then people would be better, strict even but you can't be strict all that when people are doing other things outside. Clinics are all-over, for me personally I don't have one... but people have clinics all-over, small ones, big ones, they have, so those ones can affect their work, you see when you are working and you also have your clinic somewhere, you will be thinking of money, oh...let me do and go to my clinic and get money, you don't concentrate, that is the problem and it has happened and it's very hard to

reverse it, hmm..., commercialisation, they have commercialised even the training of health workers, all of it, money, for me by the way when I first trained, it was not commercialised. I qualified in 1996 from Gulu clinical officer's school but our training was not commercialised,

Interviewer: No paying of money?

Respondent: No, it was strictly government, you enter as government and you come out as trained staunch person but these days, you find someone who hasn't passed well, because of the money, has paid some money and gone to train and has become a clinical officer, what do you expect out of such a clinical officer, nothing good of course because they have paid money, the back ground alone but for us it was government. We did interview those days, the interview was in this training school, and they took us from here, we were given admission, we went for the training, no payment of money, you just pay your personal things and go to school and train freely

Interviewer: I guess some of us missed that

Respondent: They could even give us money we missed that time, you missed it, for you, you paid money?

Interviewer: Definitely...

Respondent: You paid money for?

Interviewer: Of course now days we pay tuition

Respondent: What did you do?

Interviewer: Nursing

Respondent: You paid it?

Interviewer: Yes

Respondent: You paid the money and that is what is happening, for us, I think we were the last lot, after us they started now this commercialisation, for us they used to even give us money, eh...they would give us money but paying money for education it is hard, that is why when a person comes out, if it is not a very good person, he may not even be willing to help the patient because first of all, you have wasted a lot of money, you want to regain...

Interviewer: Ok, back to our interview, do you think the patients are dying in the community without presenting to the hospital?

Respondent: The what?

Interviewer: Patients, do you think they are dying out there without coming to the hospital

Respondent: Yes they do

Interviewer: Why do you think that is happening?

Respondent: First of all, some of them are poor, poverty, number one is poverty, and maybe they cannot even afford to climb on the vehicle and come and meet the expenses here, so he fears. And also even cultural beliefs can affect them, some of them are still going to witch doctors up to now.

Interviewer: And they believe that they work?

Respondent: They believe and they are even having wrangles in the village there, loggerheads with the neighbours that the neighbour has bewitched them because he has gone to the witch doctor and the witch doctor has said it's your neighbour, have you seen?, so that makes them to die from home

Interviewer: That is really sad

Respondent: They are, these dying from home, dying from home and some of them just have bad attitude, some of them say now if I go to the hospital, who will help me, I don't know any person there, if I go, I may not get help, that one is their attitude

Interviewer: Ok, then in your opinion, what are the two most important things ministry of health should do to improve outcomes

Respondent: The what?

Interviewer: What can ministry of health do?

Respondent: To?

Interviewer: Improve outcomes

Respondent: Outcomes of care for RHD?

Interviewer: Just in general

Respondent: Health, health is general

Interviewer: Or particularly in RHD

Respondent: Ministry of health maybe..., maybe on the side of life drugs, they can do something but of course I can't say they can do something on the part of maybe the motivation of health workers like what their salaries and whatever you know they also just wait on the decision but on the side of the drugs and personnel, they may do something because first they do sit down and budget and if they would increase on their budget for the drugs because I can see here they give us the drugs 3 quarterly, 3 monthly but these 3 months, you just use the drugs for one and half months and the drugs are finished, the number of people, they should consider the population and then they budget, you know people are than our population of these days, it seems they are still using the budget of the 1990's but they are not budgeting for this population of almost 40 million-Uganda now harbours about 40 million people, they are still giving a population of 10 million because the drugs they give here it spends around one and half months, sometimes one month out of stock and the rest of the two months, we are there buying drugs

Interviewer: Buying what?

Respondent: Buying all the things like the last two weeks, I was in the ward and people were buying cannulas, these yellow ones, cannulas, it was not in stock, it was out of stock, even sometimes gloves for examination, things here like alcohol sometimes they run out of stock, JIK, whatever, so for them, they plan for a smaller population. They should be planning and give the drugs for three months for a greater population and then that one also will lead them to increase the budget...the funding and then the personnel, they should either have a recruitment for health personnel so that at least you may have enough and then those ones on the ground, should be having on-going training so that they can be trained and they take care of the patients properly

Interviewer: ok, alright, thank you for giving us your time and accepting to participate, I know whatever your views has been will help us and the government in trying to figure out a better way to improve care for RHD patients

Respondent: It was also good, my answers may not be so good

Interviewer: No, all answers are right, we don't have wrong answers, those were your views and we welcome them

Respondent: It's okay

Interviewer: Yes, thank you

Transcribed data for recording 181221_ 0230

Participant ID	HW 010 - Lira
Age	■
Date	21 st /Dec/2018
Venue	LRRH
Interviewer	

Interviewer: Thank you so much, Good afternoon,

Respondent: Good afternoon.

Interviewer: Basically we are conducting this to determine how best we can provide care for RHD patients, so our major objective is to identify local barriers and enablers of RHD prevention and care with in this place. You feel free there are no right or wrong answers and you can be frank with your opinions and share with us all you have since all data here will be confidential and we won't have any link to your identity or any comments that you provide today, so to start with, tell me about yourself,

Interviewer: How old are you?

Respondent: ■

Interviewer: Okay, your qualification?

Respondent: Physician.

Interviewer: where, where was your training?

Respondent: ■■■■■

Interviewer: Okay, how long have you been qualified?

Respondent: ■■■■■

Interviewer: ■

Respondent: ■■■■■

Interviewer: Okay and how long have you worked in Lira regional referral Hospital?

Respondent: ■■■■■

Interviewer: 8, [REDACTED], do you mind describing like the kind of patients you see, the common illnesses you come across?

Respondent: The common illnesses are usually the, the infectious diseases, common ones are HIV related problems, malaria, then respiratory tract infections like pneumonia, TB then there are others which are related to nutrition disorders which is attributed to mal absorption disorders then I see also heart diseases especially in young children and those ones age around 20 to 40 ,then there are heart diseases also in elderly patients which are usually attributed to hypertension and then there are some other cases of heart diseases we see, which are like dilated heart disorders and then those ones in sickle cell and other heart disorders but the rheumatic heart disease cuts across up to older age groups .Then we have also apart from heart diseases we have hypertension ,diabetes, and then those ones are the commonest ones and the liver diseases especially hepatitis B, liver cirrhosis, liver cancers, and then other forms of cancers are actually now common especially non estrogen lymphomas in adults and then Burkett's in children those are the common disorders we usually see in our environment.

Interviewer: Okay, thank you so much, so tell me a bit about your training on RHD, have you received any specific training during school?

Respondent: Me in particular I have been involved in heart disease management especially those ones who were in the 4c by then that is Mulago the ward meant for cardiac diseases, so I was involved in managing of these patients and mostly doing echocardiographs for those who cannot afford doing them from other places and then those managing those ones who were admitted with heart diseases, those are medically, who needed medical treatment so we have had several what they call horizontal trainings on management of heart patients.

Interviewer: So was that during, when? Before graduation or after graduation?

Respondent: Before that is when I was still there at Mulago before leaving that place this excludes this is not with in the 8 years because with in the 8 years we have just had the training concerning the management of Rheumatic heart disease in a study which was conducted much more earlier on how to use the v scan,

Interviewer: Okay

Respondent: Earlier on

Interviewer: So do you still remember when it was done and who conducted the training?

Respondent: Which one which training?

Interviewer: The one for rheumatic heart disease, what you just mentioned about using V scans

Respondent: The rheumatic heart disease training okay there is one which was about using V scans i think about 2 years ago my memory does...but that is about two years ago and I think that was yeah two years ago early last year that is now coming to two years yeah and then there is another one where I was facilitating the training for the, the community people on detecting rheumatic heart diseases, I was one of the facilitators. That was also about the same time

Interviewer: Okay

Respondent: Yes

Interviewer: Alright, then how many patients with RHD do you see let's say per week?

Respondent: The new ones at least I would catch like two 2, 2 new ones those ones are usually in the ward but the old ones actually I can see between 3 -5 but sometimes they pick and meaning that most times you get them when they have now presented with heart failure

Interviewer: Okay, are these in patients or both in patients and out patients?

Respondent: Ahh usually they are inpatients cause outpatients we have actually had issues of movement of the clinic so the clinic is now more not helping so much on the general medical clinic but otherwise in the outpatients we would get an equal amount especially you can get like about 2-3 new cases that is in outpatient basis but of course that was based on clinical judgment not usually based on other methods of evidence. Yeah

Interviewer: Okay then what's your understanding of the cause of rheumatic heart disease

Respondent: The cause of rheumatic heart disease as in how what predisposes it or what causes it?

Interviewer: What brings it about?

Respondent: Ahh! rheumatic heart disease is just from an infection with streptococcus which is beta hemolytic basically due to throat infection variant 13, so you usually get a throat infection as a risk factor and locally here usually they do local cutting of people's throats and they get local cutting of the tooth and some people also say they are kind of scooping pus from people's children's throats those are actually the things that predispose these peoples to infection, throat infection and eventually now present with heart diseases that's rheumatic heart diseases sometimes later. But others sometimes get throat infections from home and they are not treated because they have problems of transport, access to the hospital, the place is far and also the practices we have poor health seeking behavior in this this region people don't really take their children or those ones who are sick to the hospital immediately just because of poverty or because of their attributes of their practices which they think throat infection is a minor thing doesn't need to be seen

by the medical person first so we tend to use more of over the counter medicines, drug shops we buy drugs and so on those are the things that usually predispose most our patients to these throat infections which is poorly treated and you end up with acute rheumatic fever and eventually rheumatic heart disease. And we usually see them late, those ones who behave like that, we usually see them late. But also routine check for patients for acute rheumatic fever has not been there before and so some patients are actually misdiagnosed, there is malaria or other joint or throat infections or other chest infections and they proceed to rheumatic heart disease eventually which we then see them with heart failure but with the event of the new whatever presented, I mean the program which has presented its self here now for about a year or so, it's easier now at least to help in case detection but down grass route it's difficult so we usually miss, so the actual cause is actually from the beta hemolytic strep pneumoniae but predisposing factors are pretty many with in this community and we see many of them really.

Interviewer: Then what were you told that can be done to prevent rheumatic heart disease?

Respondent: What I know it is early detection is numbers one and number two, it is about prevention and this prevention is usually when you have a throat infection, you just be treated at quite an early stage, of course there are issues of vaccination but not so many people have been involved in such. And then the other thing is that rheumatic heart disease is best prevented than actually to catch, to catch it. community aspects we haven't yet really gone down to find out what happens there apart from the program that has been running which has been trying to reach those communities but in the hospital we just focus about treatment and most times we have been focusing about treatment of complications and because they present late with complications, that's where we see them and being a referral facility, we see the really sick people who are referred to us that's what we usually see.

Interviewer: Okay, and then the treatment options?

Respondent: The treatment options we have antibiotics but they are usually out of stock in a year, you find particular options you need to have, they are out of stock like more than 50% of the time, so before we really had issues to do with the medications to give them but of recent we have had some improvement in the medications to give them, the penicillins have been available but of course the stock out has been actually quite frequent like just in the last 3-4, 5 months ago we didn't even have those medication of course except for the project which has its own medications. But from way before that is over 7-8 years ago it has been a problem to access these drugs because most of the people have to buy these drugs, yeah

Interviewer: What's your understanding of the long term prognosis of rheumatic heart disease?

Respondent: The long term prognosis treated early good outcome good prognosis treated late creates a lot of problem in terms of medical pill burden, financial losses, complications from heart diseases heart failures with eventually the patients may succumb to heart failure if they don't really attend the clinics cardiac clinics but when caught early the prognosis is good really when caught early but caught late we have had problems of issues to do with transplants ,valve replacement which is very costly and this place is one of the highest poverty levels with highest poverty levels in the country I think we are if not number 2 or 3 just in terms of poverty levels all of the country so people don't afford to have those expensive cardiac surgeries and eventually they end up dying but when caught early ,it has a good prognosis but when caught late the prognosis usually tends to be poor since even the management becomes a little bit expensive and complicated for the local community to sustain it.

Interviewer: Do you recall the last patient you saw with RHD

Respondent: This morning

Interviewer: Okay you could just give me their brief summary of their visit like

Respondent: This morning,

Interviewer: Yes

Respondent: Ah,this is a the child who is about I think is fourteen, I think fourteen years has been on and off in the hospital has clinically presented with features of congestive cardiac failure the heart all the valves are affected, regurgitation of all the valve and dilatations of the heart chambers with ejection fraction very reduced less than 40, can't walk, and aaah can't sleep at night without coughing excessively, and has been really weak but that has been because the child first all of did not, did not come back, and the reason they gave for not coming back for drugs was that they did not have transport, and secondly the care taker says that they didn't have any other person to help them do so from home so they couldn't carry the young girl to the hospital. But general over look she is picking up and I think she may eventually need valve replacement but of course being poor even at this level, it may be quiet difficult for her to access those valve replacement because the stage where she is the heart failure is one where, you now need those cardiac assisted valves , those mechanical ones and maybe valve replacement, yeah the ICDs may benefit the child may benefit from those ICDS but coming from a poor family that you can't even come back for just a medical review for a cardiac disease is bad enough so those are the kind of patients we eventually end up seeing, yeah

Interviewer: Okay quite sad for that one, then on average like what is the average age for your patients?

Respondent: The ages are usually, the ones I have been seeing are between, between 5 I see them between 5 up to about 20 for children then there is that group I usually find late about 40s they, usually present when they are now having other issues then the Rheumatic heart disease just got worst that's why they present back to the hospital, but the Majority are age between 5 to 20 the ones I see

Interviewer: Okay, are most of them in school or and working or most of them just left work and are out of school because of the illness?

Respondent: These are children, they don't work most of the children are actually because of illnesses, they are actually the school drop outs ,majority of them very few are struggling with school because they have problems of first of all the distances, they move to schools on foot, then also the care takers, then leave alone that those ones who go to school they have problems that they lack those ones who can take them to school, and sometimes they even default on coming back for medicine and then they eventually develop heart failure from home then they just drop off school and because of a lot of financial constraints they end up just staying at home and parents prefer treating I mean they give preferential treatment to children without heart diseases but sometime it's unfortunate you may find like 2 or 3 children from the same family have the same thing so sometimes it becomes also a little bit stressful for the families but the older people usually they are not doing anything because they have been ill, they can't move , exhaustion intolerance they are usually they are in the vicious cycle of poverty, they are sick, they can't do anything then also poverty sets in because they are doing nothing and yet you need to spend on drugs spend money on drugs and so on so they are really not productive in their own communities because of illnesses.

Interviewer: Okay

Respondent: Yes

Interviewer: And these the ones you interact with are they aware of the link between sore throat, acute rheumatic fever and rheumatic heart disease?

Respondent: They are beginning to pick because of this research and ahh the cardiac program which has started with in the hospital they are beginning to pick but before it was absolutely not connected absolutely it is me as a medical person who knew but the community had their own way of attributing heart diseases just like I give you an example of three children all with rheumatic heart disease in the same family they said it was because of these traditional witch crafts at home that is why all the three children had rheumatic heart disease basically it shows that most people didn't know much about rheumatic heart disease they know there is a heart disease but they didn't know the one that they could do something about and the

commonest one near them because the commonest here is rheumatic heart disease in more than actually even 50 60% is just the majority basically.

Interviewer: And then these ones who present, what symptoms do they always describe to you

Respondent : Most of them just present with symptoms of heart failure they can't walk, lower limb swelling, they get tired, they feel dizzy some people come when they have collapsed , others come when they can't sit, can't breathe, can't sleep, with excessive cough others even come coughing blood so they come very sick.

Interviewer: And then how is the follow up and adherence?

Respondent: Before this project, Makerere guys from Uganda Heart Institute., we had tried to have a program where we were giving them injection of benzathine penicillin every four weeks but of course the guideline was saying three weeks but because of transport problems and they come from far and so on we just had to increase one more week so at least we do one month. And they would basically come for the treatment sometimes they would buy some times the hospital has but stock out are actually quite a number. And before also this this rheumatic heart disease program which is from Makerere the one from Heart Institute before that one, the mortality was a little bit high so most of them would also die actually, but now at least they are they are living a more reasonable life the quality of life is I think more reasonable now.

Interviewer: That's nice to hear and then what sorts of barriers do they commonly state to getting care that they need?

Respondent: Transport, distance from home, money, stock out of drugs from the hospital, lack of caretakers from home, some of them they get constraints because they get pregnant and they do other things some of them are orphans and some of them actually don't even have relatives who actually care about them they bring them when they are already sick, then most of them didn't know even what to do with rheumatic heart disease if you have they put for you a lot of restrictions this is usually the medical workers who don't know what to do initially so the restrictions were pretty many and the patients would not adhere to because some of them were not evidence based you give unnecessary restrictions and patients would default because they had been given many restrictions, the injections we were giving benzathine we were giving without even local anesthesia painful they don't come back because they are fearing pain, the other one is that the drugs for heart diseases sometimes we order for them from National Medical Stores then you get supplies late or even they don't supply or if they do they bring very few that gets finished quickly then also the other thing is that the doctors are kind of now becoming apathetic because the patients are sick you want to do

something and a doctor as you don't have what to do for them because what you want do, you can't do like by then you can't do Echocardiography, you can't do ECG ,you can't do laboratory test for these people so you also join the bandwagon of being helpless.

The other thing is that even the administrators or the politicians those ones in charge of financial control they didn't know really the magnitude of heart diseases, they usually get to know only when you are when they are burrying one and by then also when they say you have a heart disease, most people think you are going to die so they tend to even spend less on you and they think now once you have a heart disease, it is some kind of a charity which has to come and pay for your treatment short of it you have to die ,some kind of a misconception trend which has been there though the treatment cost has been high ,then there are those ones who may want something done, they come to the hospital early before the heart failure has gone worst , then they are told they may need those days, we didn't have any surgeries done much in Mulago but right now Mulago is doing a lot but still some people instead of going to Mulago, because of lack of knowledge they still think that they have to go to India for the operation because they think it is only in India because they lack the information ,so there is complete lack of knowledge and information in the community about heart diseases and rheumatic heart disease to be specific there is really a huge gap in information there and the resources to use for making diagnosis like as I said earlier on we don't have diagnostic equipment to be used so most of these patient initially we were referring them to Mulago to at least do for us an Echo may be once a year and that is it the rest you use your clinical judgment.

Then the other thing is that you have some patients when they improve they don't want come back then also you have some patients who after you see them, you are sure they will come back, they travel away like others they go to Sudan to look for money and by the time you are seeing them next they are very sick or they have gone to the lake side like Amolatar for fishing the next time you see them they are very sick. Then those ones who actually are in town some of them the they are really without parents and those ones you only see them once in a while when they appear back in heart failure and also we didn't have preventive activities going on to actively look for the patients who are exposed to this streptococcus so they are identified earlier and treated, we don't have actually a protocol which is supported by the government and to actively look for it and diagnose, it just the way they do for Malaria, because for malaria you have RDT quickly microscopy you have the diagnosis for rheumatic heart disease sort eee swabs of the throat , transporting it to Kampala I mean some of the facilities like for culture and all that is missing and most hospitals don't have them except for teaching institutions. Yeah

Interviewer: Okay and then okay now according to you as a health worker, which barriers do you face in taking care of them?

Respondent: It is just about, one for those who come the barriers I find is that first of all they come late so there is a problem of diagnostic tools to be used ,number two the drugs they are probably there in inadequate amount or not there, number three people who get trained during the time they are in the unit they may get transferred they may get moved to another place, they may retire they may opt for another job, that interferes with the institutional memory of those who you can use for treating these patients because you can't treat them alone. And then the other one is in the data collection and use most times patients come, we do all that we have to diagnose, investigate, treat, they go home and it is not captured anywhere and they go home so it creates an illusion as if the patients are few because there is poor data capturing by the health workers this is partly because Rheumatic heart disease is not given special attention like things like HIV where the data cannot be missed anywhere, if you give somebody treatment for HIV they won't miss it but for rheumatic heart disease they will look like it is some other condition and so there is no special data collection systems for heart diseases that has been there. It has been bundled up with other diseases and data use has not been there therefore most times when it comes to budgeting you find the data is scanty and people don't even pay much attention in buying the drugs for rheumatic heart disease or buying the reagents to make the or prioritizing the diagnosis of rheumatic heart disease and also when it comes to the community aspect as a doctor you hardly hear any group coming to talk about rheumatic heart disease except from Uganda heart institute I have never had any genuine group that comes to tell me about rheumatic heart disease and how we can prevent and so on and so forth and then there is an aspect where people think that heart diseases is supposed to be referred yeah most health workers think that it is for other people it is not theirs it's for some selected few and they perceive it is if it is for some people it is not theirs so the way it is treated also creates a lot of challenge and because there is no some kind of cohesion and then lastly those ones those one the patients we see the mortality is high and sometimes the patients start to correlate the death of another person to be like to determine their prognosis and yet it is a difficult different thing basically yeah. Yeah that is I think what is there

Interviewer: I don't know If you, you i think we already talked about this the barriers that you perceive these patients face, yeah you mentioned a few of them so just briefly do you think the administration and leadership of the district is doing well?

Respondent: Doing well in what aspect?

Interviewer: In terms of health

Respondent. I don't know

Interviewer: Laughs, okay what hasn't the district the leadership in the district not done well what do you think they are not doing well?

Respondent: they have not prioritized the heart diseases that's one thing I know that's the part they have not really prioritized prevention diagnosis and treatment of heart diseases

Interviewer: So why do you think they haven't really prioritized it so much?

Respondent: I think there has been less emphasis put on it I don't know whether it is the money or what I don't know I don't know I can't speak for them I don't know but they have not done really much about it may be they themselves also they really need to be informed about the magnitude of the problem may be they also don't know I don't know may be data use is poor so they can't really whatever figure out the burden as such.

Interviewer: And then about the funding of health care in general and then with RHD in particular, are you happy about it?

Respondent: Health care funding has been poor and they usually emphasis key priority areas then priority of course is based on each and every institution what their priorities are and you can only set something to be your priority if you know the problem if you know the magnitude of the problem and as I told you earlier on, the data use in data collection capturing, collection, recording analysis and use of in the hospitals concerning heart diseases is extremely poor so it doesn't really reflect what is on the ground and of course as you know there is a trend now that where the money is put that's where you have more data collected for you and other places where money is not put data will not be collected and it will appear as if it is not there when it is there and for us at the front line medical personnel treating these patients we find them but to them it is not a big issue because they have not taken a deliberate step to look for these cases record them and holistically handle it according to the disease burden.

Interviewer: So you feel we have a big problem with the record system?

Respondent: Record system terrible, the financing system terrible

Interviewer: And it could be affecting the financing

Respondent: Exactly it is affecting also because once you don't, once what is not recorded it means it is not done therefore the same principle applies to them when it comes to budgeting.

Interviewer: Okay

Respondent: So they look as if it is not a big problem but it is

Interviewer: I get it

Respondent: Then what about the health workers are you happy about the numbers the qualifications that you have at the hospital

Respondent: Health workers are few health workers are pretty few and they are very demotivated and they also lack knowledge in managing most of these cases of heart diseases and as I told you most people run where there is money so where you don't get allowances for the activities, you don't go there so cardiac diseases you don't see allowances so no one wants to go where there is no allowance. HIV program you find people there, TB program you find people there

Interviewer: Because there are allowances?

Respondent: Because there are allowances for people who get involved in those activities

Interviewer: So you think there should be motivation of people?

Respondent: There has to be more motivation for these groups leave alone finances, first of all they need training they need to be motivated and they need to be followed up, you need to know where they are, they need to like follow what they are doing, they need to do for them refresher training but otherwise the staff levels we have is critically low and worst they keep switching them from one area to the another you will find you trained this time in heart diseases tomorrow they are in maternity doing antenatal care and ,and you can't really stop them from that but ahh most of these staff have to be oriented in that direction they need to be trained actually refresher training and courses is vital for them and I would preferably choose a model of having like a selected people who get more training in care of cardiac patients more of a specialized way of keeping the nurses in one area such that it becomes also difficult for people to keep them moving randomly so if Uganda government can take that module where you say you want cardiac nurses you only study cardiac nursing and special training even if you go to another district or another hospital you just join the group of people who are managing cardiac diseases on that side just the same as those ones who manage children ,those who manage neonates ,those who manage diabetes, those who manage hypertension I mean those who manage accident and emergencies there has to be some kind of a structured way of doing nursing than the approach we use now because the approach we use now does not encourage excellency it encourages mediocrity you get more of everything and nothing in detail.

Interviewer: Alright, and then how do you perceive the quality of care the health workers are giving?

Respondent: The quality, okay before I think it was terrible and I think out of ten I would give it 30 I mean out of 100 I would give 30 and that is 30% I don't really think they are giving the care which these people deserve truthfully I may even give less but with the program which is going on now for this detection of rheumatic heart disease by Uganda Heart Institute down here it has first of all it has relieved us of the

burden first of all getting the patients investigating these patients ,giving them medicines, following them up, recording, it is as if they have removed some one heavy load away so it is for now being done by the research group but the only trouble is when the research group leaves they will leave those patients to who?
Thank you

Interviewer: Laughs, okay and then the waiting time, okay how best do you think the quality of care can be improved?

Respondent: The waiting time, okay quality of care the most important thing is actually, it should be by these refresher courses for people to know how to detect the cases to start with, number two diagnostic tools to be used for diagnosis of rheumatic heart disease cases it has to be available. For the last 2 years somehow we have been getting fresh air because we are using the v scan that is courtesy of a research but soon it will go back to what it was because now we can do basic scans we can detect the cases but as soon as they take the machines back we are back to where they found us except that we will have the knowledge and we will sit back and do the same thing that we were doing before treating on guess work then there has to be a special clinic really for we like opening cardiac clinic specifically so as these patients are given the attention they deserve just like HIV patients so as you know who to be seen first, seen quickly, say no, who to refer, who to stay, who to admit in that way if we can have a system that would have them seen in the out patients or their own clinic well and good. Then also to improve their services there are areas like the cardiac beds you hardly find a cardiac bed in the hospital apart from in the in the ICU which are few beds the other ones they behave as if they are cardiac beds but they are just modified cardiac beds they are just beds and others don't even lift the cardiac beds are lacking including even the resuscitation tools things to resuscitate cardiac patients emergency cardiac drugs I hardly see any, I hardly see any apart from a few you get from the theatre you don't see any out you don't even see emergency cardiac trolley or whether basic life support trolley or advanced life support trolley with cardiac drugs things like defibrillators I mean all those things, tools to use with drugs and all that zero. It's just by the name that it should be there but those are the things that would probably if they are there would improve the quality of care otherwise we are practicing almost a half like bush medicine emergency medicine in the bush.

Interviewer: Laughs, Okay, what about the medication do think they are available?

Respondent: The medications I,

Interviewer: Benzathine and anticoagulation medicine?

Respondent: With the program from the heart institute this research they have been there for those patients but before that and am quite sure even after that if there is no, no any post program planning done for those patients we will go back to where we were where drugs are procured.

Interviewer: What about in the hospital

Respondent: Drugs are few

Interviewer: In the pharmacy

Respondent: They are there, few, if it is brought but greater majority as said earlier on it is out of stock for most part of the year.

Interviewer: Okay

Respondent: Yes

Interviewer: Ahh, you talked about diagnostics being available

Respondent: Diagnostics are not available but right now we are riding on the back of the researches being done in the hospital by heart institute so that's what we are benefiting from by sending those patients there but of course once they leave we go back to square zero

Interviewer: Okay, and then do you have guidelines and protocols for RHD care?

Respondent: We are using the national guide the national guidelines the one from Heart Institute but of course me as a doctor I use other two guidelines the one for American Heart Association, the European Cardiac Assoc society I combine those ones to use but we have our guideline by Uganda Heart Institute that it is used and is working well.

Interviewer: Okay that's nice, lastly, we talk about perception of patient outcomes generally do you think that they, they are getting the care that they need especially surgery?

Respondent: No, no

Interviewer: Why is that so?

Respondent: I think it is finances, these patients, the surgical aspect, most of them you refer some of them need more advanced surgeries and they need to be referred may be to India because of lack of tools to use from that side of heart institute so they tell them that they need to be sent to India but the cases that end up in Mulago where they can do with the tools they have ,they have actually been doing them and, and with really I would say with 100% good out comes, those ones they have done I think they have scored almost

100% I haven't heard any scenario where they have failed okay may be they are there but the failure rates of those ones I have sent has been zero so those ones

Interviewer: Okay meaning they are doing well

Respondent: Yes it's only those they have deferred because of the reasons of the tools to be used on them

Interviewer: Then do you have any patient safety concerns and quality of care concerns?

Respondent: The safety concerns is that they don't know who is supposed to be like their main source of help so sometimes when you send them down there to the clinics I mean in the health centers for them to be injected some times they think they may be injected by someone who doesn't know how to inject properly so it is issue to do with pain they may inject without lignocaine the pain attributed to the injection that's basically their worries of course the safety concerns of the surgeries to be done which are done in heart institute they are usually minor because it is not a safety concern it's more of worries whether it can be done because most of these surgeries were not done in Uganda so they would only be concerned whether it can it can also be done now in Uganda that's all.

Interviewer: Then do you have you do you think there are preventable deaths that occur in the hospital?

Respondent: A million, too many.

Interviewer: Why do you think so?

Respondent: Why do I think so, when you come with heart failure and you don't have a basic drug like Lasix and you die from volume overload is that death from a cause you cannot prevent?, Isn't it so?

Interviewer: Yeah

Respondent: Yes, so, there are deaths which you can prevent, patients come with heart rate over 160 you don't have IV drugs to slow the heart rate down they end up with stroke or a myocardial infarct just because you can't slow it down yeah they are preventable causes really .

Interviewer: So due to lack of medicines and supplies

Respondent: Medicines and yeah medicines and supplies to be used including diagnostics ECG for example not there in the hospital apart from the one of the research it's not there it can't be done

Interviewer: I see

Respondent: So you make a lot of diagnosis from ECG alone but if you can't make that diagnosis then you die you will die from something they would have stopped, so there are a bunch of people who die from preventable causes, yes

Interviewer: And do you think there are patients who dying in the community without presenting to the hospital?

Respondent: A bunch of them because I have gone for burials and when they talk you can co relate the history to the cause of death and you can tell this is from a heart disease ,you can tell, so many die there

Interviewer: And why you think those ones are actually not coming to the hospital?

Respondent : It's partly poverty, partly ignorance, partly lack of information of services offered, partly because of frustration, social issues at home, transport or partly the services are not available where they stay, they have to trek a long distance to the next best place where they can get a doctor like you see most doctors now are only found in health Centre 4s and hospitals even health Centre 4s the doctors are not available and even if they are available they may not be I mean they may not be I mean more, more, able to comprehensively handle these cases yeah they are not competent enough.

Interviewer: Thank you so much now in your opinion what are like give me one or two most important things ministry of health could do to improve out comes

Respondent: Ministry of health, let them improve diagnostics and then supplies of the drugs and then diagnostics, supplies of drugs then they, they need to prioritize heart diseases just like the way they prioritize other diseases where there is priority they put funds and where they put funds there are results you don't put funds no results.

Interviewer: Okay, thank you so much, do you have any other thing to say?

Respondent: Nothing.

Interviewer: Nothing, okay, thank you so much for accepting to participate in this interview ahh your views will really help us in making care of rheumatic heart disease better.

Respondent; Alright, good luck

Interviewer: Thank you.

Interviewer: So for how long have you been working in lira regional hospital?

Respondent: Since [REDACTED]

Interviewer: [REDACTED]

Respondent: I have been here

Interviewer: [REDACTED]

Respondent: Yes

Interviewer: So briefly which kind of patients do you usually see or common illnesses you meet in your day to day work

Respondent: In my day to day work, it's like it cuts across all conditions

Interviewer: Yes

Respondent: but mostly we get ladies with PID that is the most common disease which are clocking in mostly

Interviewer: Ok

Respondent; Yes

Respondent: Do you do echoes?

Respondent: Yes

Interviewer: what are common conditions you meet in that group?

Respondent: In echoes we get patients with hypertensive heart disease, we get with DCM, we get patients with valve heart diseases

Interviewer; Ok, so like have you ever got any training on RHD like training in school

Respondent: Yes we were trained on like rheumatic fever and heart disease mostly in my training in the nursing side

Interviewer: Ok

Respondent: We have ever had that I think it was in 2007 when we had also the other group which is generalised on the heart problem

Interviewer; Ok

Respondent: Yes

Interviewer: So it was a training after graduation

Respondent: yes

Interviewer: Ok, when was it, you said 2017

Respondent: Yes, the other group which your research followed, the other one

Interviewer: Where did they have the training?

Respondent: It was here, they trained us for one day here

Interviewer: Ok, like do you remember the group, the names of the people who trained you

Respondent: We had, the few I can remember.

Interviewer: Ok, about the patients you see like how many patients of RHD do you meet, let's say in a week

Respondent: In a week?

Interviewer: Yes

Respondent: It depends because at times you get other days when you don't have them but you also be blessed in other week's maybe 2-3 within a week

Interviewer: In a week?

Respondent: Yes

Interviewer; ok

Respondent: They are not consistent but when they come, you get them because others you get them like incidental findings also maybe somebody has requested something else for ultra sound maybe abdominal ultra sound, when you peep on the heart or you see the other general body condition till now on your heart incidental findings, you will get the patient who has this one or he has RHD or any other cardiac diseases

Interviewer: Ok are these patients mainly inpatients or outpatients

Respondent: Ok they are both inpatients and out patients because at times they also move un diagnosed

Interviewer: Meaning you always get someone that is actually being left out

Respondent: Yes

Interviewer: Ok

Respondent: They may send us with some other conditions, maybe a patient is having lower abdominal pain, chest pain but when you access the patient, you find when the patient has cardiac disease, for me, I will be prompted a part from doing ultra sound. I have to go ahead and do echo and after my findings, I get the cardiac disease

Interviewer: Then where do you refer those patients?

Respondent: These patients when they are within the age group that fits rheumatic from 5 years to 18 years, is it 5 or 3-18 around there, I send them to rheumatic clinic but those ones above that age, I always refer them to Dr or I may call or I always tell her to see them and I direct them to her

Interviewer: Ok, let's say on average, how many people would you actually incidentally get

Respondent: By doing ultra sound or maybe just by peeping into the heart

Interviewer: Peeping into the heart?

Respondent: Yes, in a month we can get like 5-10

Interviewer: 5-10?

Respondent: Yes

Interviewer: Wow, it's quite a big number

Respondent: It's a big number, many actually missed out when they have not captured them

Interviewer: Ok

Respondent: Yes

Interviewer: Something, ok, about what you have been taught, ok, what is your understanding of what causes RHD.

Respondent: RHD is just a condition with a sore throat and it's caused by a group of staphylococcus group A, group B not A, I think its group B and if not managed well, a sore throat, they can migrate because they like the tissues around the valves, they migrate to the

valves fast leading intobecause it first starts with fever, a sore throat, a sore throat at that state is still acute rheumatic fever and If it's not managed well or because at times they also under look it they may manage it as malaria and in our setting, there is no those swab whatever.....throat swabbing and those investigations, so they can manage it as maybe, malaria or other infections. so if not managed well, it can migrate into the valves leading to RHD

Interviewer: Ok

Respondent: Yes

Interviewer: You have already answered my second question...both laughs. I was going to ask you about the link between sore throat and RHD

Respondent: Ok...laughs

Interviewer: Ok, what were you taught that can be done to prevent RHD?

Respondent: One, when somebody has sore throat, it should be managed well with a good anti biotics and it can be cured, if its managed well, they put the patient on anti biotics, the patients get cured, so that's the stage of fever.....both laughs and if the patient is managed so well, the patient will not get RHD

Interviewer: Ok, any other thing?

Respondent: Then the community should be sensitised on how this disease is got and how they should go about it.if they have realise or if the child has a sore throat, they take to the hospital as early as possible for proper management then on the other hand also.

Interviewer: I see like what we should do?

Respondent: The staff

Interviewer: Yes

Respondent: The staff is not yet well sensitised on RHD or sore throat so if the medical workers are sensitised well and they have a positive attitude towards managing sore throat, we would reduce on at least the number of patients who get RHD

Interviewer; And then do you know of the treatment option for RHD

Respondent: The treatment option is there but you see at times for me I don't concentrate but I just try

Interviewer: But you like remember what you were taught...both laughs, they can give

Respondent: When someone has a sore throat, they can treat with Amoxicillin but I think 10-14 days but am not very sure and then if someone really has the RHD, they also give benzathine, they treat with benzathine IM, at least there are those ones they put for a little time, there are those ones they put for sometimes depending on I think the stability of the condition. I think that is the only thing I know about it laughs

Interviewer: Ok what of those with severe diseases

Respondent: They can because there are those ones with stenosis, they can refer them for surgery like **Baillie**, and then there are those one with valve replacement

Interviewer: Ok

Respondent: Yes

Interviewer: Ok, any other thing for the treatment options?

Respondent: Treatment opinions, those are the few I can remember

Interviewer: Alright, thank you and then what is your understanding of the long term prognosis of RHD?

Respondent: The long term prognosis of RHD, if it's not managed properly and in management it involves now a group of people from the patient, attendants, the care givers and even their doctor. If we stand together as a group managing and we are carrying out the correct thing and giving out the correct thing to these people, the chances for them to at least to push for some days but if we are not coordinated in our management, we end up losing this patient

Interviewer: Ok

Respondent: Yes

Interviewer: This is about you encounter with the RHD patient, ok like when was the last patient the last time you saw an RHD patient?

Respondent: The last time I think that was in November

Interviewer: November?

Respondent: Yes

Interviewer: Ok, would you briefly summarise your encounter with this patient

Respondent: This lady came from OPD, she was an outpatient, I think she was around, around early twenties, she was sent for pelvic inflammatory disease but when I encountered the patient, I had already prepared them for a pelvic scan but the patient was now on the table, I was examining her for pelvic scan doing ultra sound, I realised here breathing was not proper, she was having some difficulties in breathing and she would, she told me she was feeling tired on lying flat, then I told her can you sit up, so when she was sitting up, she felt abit relieved and I told her to go and lie again, then again she stated coughing and she was now restless, I said can you sit, then I concluded her pelvic scan and I said, can I go ahead and do for you echo because I can see you have features of heart problem, so when I saw the lady, she had a ripe thickened micro valves, there was also some reduced function and also the heart looking enlarged, so for me I also took it to be like this lady has both rheumatic and DCM so that is why now I made now two reports, for the findings and then for the echo, then I sent her tothat day I called Dr betty but she was not around, so I instructed her to take that one of the pelvic that side but for echo she had to look for Dr or go to the medical OPD on a Tuesday because she was already past the age for...both laughs for research

Interviewer: Ok so what is the average age of these patients you see with RHD, those that have come to you

Respondent: The average age?

Interviewer: Yes

Respondent: I get them from around, you can't get those one of 5 years ranging up to around....mostly there within 5 up to like 20 but there are few cases which goes past because maybe they have gone undiagnosed, so it's mainly the lower age, its mainly the lower level though we have also some cases past 20 years

Interviewer: Ok, so these people who come, are they working or they are already or they are not working

Respondent: These ones who comes with.....

Interviewer: Who come to you with RHD?

Respondent: Others are just housewives, other are students, and ok they are still in school

Interviewer: Are the majority of them at school or they are out of school

Respondent: I see the majority of them have dropped out of school, one because they feel sickly, they can't now be retained at school because they are always sick

Interviewer: Ok

Respondent: Yes

Interviewer: Ok, when you try to interact with them are they aware of the link between the sore throat, acute rheumatic fevers and RHD

Respondent: Most of them do not know, that's why I talked of sensitization has to go on, most of them do not know they just begin telling you when you inquire maybe did you have a sore throat sometimes back, they say yes, they have been doing the local tonsillectomy, you know. Whenever I feel a sore throat, they take me to a local tonsillectomy

Interviewer; Ok

Respondent: Yes

Interviewer: It seems like local tonsillectomy is a big thing

Respondent; Yes it's a big deal here ,whenever you get a sore throat, they take you for that and they don't give you anti biotics, so it's like it just ready for more infections

Interviewer: What sorts of symptoms do they usually describe to you?

Respondent: They said when this thing start, they will feel abit of fever, then they would get pain on the throat and mostly on swallowing, they feel pain then after maybe the fever can also go away without even any treatment. Others even say they make this local bicarbonate, they make to take it like the oral drug

Interviewer: laughs, and they said it cures it?

Respondent; They said its ok

Interviewer: OK

Respondent: Yes

Interviewer: Any other thing they tell you or any other symptoms they described apart from....those ones?

Respondent: The sore throat

Interviewer: Yes

Respondent: Maybe after sometimes again is when they maybe at least feeling tired, difficulties with breathing at night and they could hardly run, when they try to run, they feel easily tired and coughing when they lie down flat on bed, they tend to cough a lot

Interviewer: Ok

Respondent: Yes

Interviewer: How good is the follow up system here?

Respondent: The follow up system here I could say its good but the problem is what I said before, most of the medical workers are not also....though they are sensitised but their attitudes towards management because if somebody already has different attitudes, though he sees a rheumatic patient, RHD, how he will manage it, other things leaving this patient to move undiagnosed and at times they also don't know the criteria of management. First our patients do not get proper follow up, then at times when maybe you send them to come back ,they may come back for reviews and when there is no drugs because you know the hospital settings, there are some months when drugs are not there and they cannot afford to buy making them also to default

Interviewer: so that also affects their adherence

Respondent: Yes, it affects their adherence

Interviewer: Ok, meaning ok like at what percentage would you place their adherence

Respondent: The adherence of the patient I can give like for patients, I can give like maybe 75% because they want to get cured, they feel like they have got their disease and the drugs they are going to get it, they are willing to take it but one, when the drug is not there, they are un able to get the money and buy the drugs such thing will lower also their adherence because they are willing but the drugs are not there and maybe if they come to the hospital, there are no people willing to help them like the medics around, those ones also demoralises them, maybe they also come from far, transport to and from, maybe next time if all the medics, medical workers are sensitised on RHD, they can have on their setting within the health centre, just a unit for handling, so that they will be moving in a shorter distance that they can be managed well, that is a future plan

Interviewer: Ok

Respondent: Yes

Interviewer: And then what sorts of barriers do they commonly state to getting the care that they need

Respondent: The barriers?

Interviewer: The ones the patient tell you

Respondent laughs, one, the parents may not be in position to keep them and maybe the parents are already tired of them so whenever they come to the hospital, they have been diagnosed and they give them schedules to come. The parents are not interested, they say this one has been sick for long, it's like they have given up on this patient because they know this is a chronic illness and at the end of it, they are going to pass on, so they feel now **they** feel they are just wasting their time, so at times their response to keep bringing the patient back for review is also not there

Interviewer: Ok

Respondent: So one is attitude of the parents and guardians

Interviewer: Attendants

Respondent: Yes

Respondent: Then maybe also these patients, they need money, one for their transportation, for buying drugs which may not be there with our settings here

Interviewer: No money?

Respondent: The issue of money

Interviewer: Yes

Respondent: So they will not come back for review, it will be a barrier for their treatment then we have, we have the perception where people misconcepts on the way people may be thinking, when someone has a drug, you have to share, now you have given drugs for a rheumatic patient, someone is getting cough and they will get this same drug and he will not be getting the exact recommended doses for him or her, that one is also a hindrance

Interviewer: Ok, what other barriers do they tell you they face on getting care?

Respondent: On getting care, at times also depending on the families, others also have even no food at home, so when the patient is not feeding well they just go down which is also a barrier

Interviewer: Ok and then as health worker, which barriers do you face in taking care of these patients?

Respondent: The barriers we always get, one its early diagnosis of these patients, most of these patients, most of them are always diagnosed late and I pray the hospital settings would have a laboratory which would be doing a throat swabbing, it would help like in x-rays, a child, like around 5 years upwards up to that age, it would be like a routine, they do a swabbing when they come with a fever that we exclude this staphylococcus infections early enough, then if the medic are well sensitised and they have the attitude to manage, we would manage these patients on early diagnosis and proper treatment and they will recover but now that there is nothing for testing them, we just treat them blindly, we don't know what we are treating, that is making them to have RHD and usually in excess and the availability of drugs

If the drugs were available and we don't run out of stock for those drugs, it was going to help us in proper management

Interviewer: So you said you lack drugs?

Respondent: Yes

Interviewer: Because it's not available?

Respondent: Yes, it's not available, it's seasonal

Interviewer: Hmm

Respondent: You get some months when these drugs are not there, the other one also not there, so it needs a frequent flow in for drugs

Interviewer: Ok

Respondent: Yes

Interviewer: And then now let's say you are looking at the patients perspectives, what do you perceive that they face in getting care

Respondent: In getting care?

Interviewer: The challenges they face or the barriers they face according to your views

Respondent: In my views?

Interviewer: Yes

Respondent: These patients have a lot of challenges, one is the attitude of the medical workers, some body has come with a problem and needs assistance from you but you as a medical personnel already have a bad attitude towards the patients, you are not going to listen to the patient, you are not going to help the patient out of the problem, and even you are not going to diagnose the patient. If the patient is diagnosed, you are going out to begin because you already have a biased mind on the patient, you are not concentrating on the patient, so you are going to do your own thing which is not related to the patients' complaints that is one barrier, attitude, attitude and good relationships. Patient medical worker relationship

Interviewer: Which other barriers do you perceive?

Respondent: They face they also face stigma, even from us the medical personnel's and people outside, they may take also.....you see, misconception, they, may say this is also dying and whatever a disease that will not cure, secondly others may perceive it's the drug, I mean the disease is infectious, bringing in the stigma and they want to isolate them which is both from a medical worker or maybe from the relatives, so they need sensitisation

Interviewer: Ok

Respondent: Yes

Interviewer: Any other barriers that you perceive they face?

Respondent: I think those are the few I can say

Interviewer: Ok let's say looking at the local health system barriers, how and do you feel that the administration and leadership at the district is doing well?

Respondent: No, why I said no, there is a lot of thing happening in the health centre settings, the medics in the health centre one, they are lousy, they come late on duty around 10: 00 and they leave also very early, weekends they are almost not available in the settings and secondly they can trick, they can trick what is not for them, so because.....they like that one I am talking through experience, here was a kid you sent for me that was I think that was early December, they called me, the patient was being treated in another health centre in Orum and they said

that kid, she was a girl around 4-5 years and they said the girl had a cardiac disease so when they called me and I told them, can you bring her to the rheumatic tent, when we did the scan, it said the kid has a normal heart but they were already managing as a cardiac disease and I had seen they had already put her on bendofin, so when I repeated, you sent her again to me. I repeated and I made a report as a normal heart scan so at times its goes back to knowledge, knowledge deficient about this RHD, so that was a wrong drug for a wrong diagnosis and it's like we are doing nothing

Interviewer: Ok

Respondent: Yes

Interviewer: Do you feel like the supervision is not enough

Respondent: Yes

Interviewer: Back to those health workers are they not supervised?

Respondent: And most of them when they are going for supervision, it means there is something, there is some money, they go for money not for supervision because with supervision when they know they are going to get a token out of it, so they go once in a while depending on the location of being within the district, if it's not there, they don't go so these people are just for free, they bare just at their free leisure, so if the district could strengthen their supervision within the facilities and they are sensitised and they have a good attitude towards the management of this condition of rheumatic heart fever even we would be getting, very few patients, it's just the same way like for ultra sound, we have even ultra sound in the lower setting but people who went and read ultra sound, they have abandoned that knowledge, they have now gone to do other things, and the machine is there but no one to use them

Interviewer: The problem is with payment or the recruitment process?

Respondent: **One**, once you have read something you have to practice it

Interviewer: Hmm

Respondent: Two, they have been sponsored by the ministry of health where that are supposed to continue with that there ,three, they say the promotion level, the ministry makes you to read, they don't give the **cadre**. You don't get any payments, so people abandoned them, so it's just from the ministry down then through that hierarchy

Interviewer: So that's why you feel that they are not well?

Respondent: Yes

Interviewer: Ok, what do you think they have at least done well?

Respondent: At least they are keeping our health centre moving though.....both laughs. They are keeping the health centers well, the patients are coming there but only that they refer them more so when it's reaching to a weekend, they refer them to a referral hospital, those ones who don't need a referral

Interviewer: Because they don't want to take care of them or that they will be congested?

Respondent: They want just to decongest their health centre and the weekend

Interviewer: OK

Respondent: Yes

Interviewer: What about the funding of health care in general, and let's say RHD in particular, what do you feel it's good about it or you also feel like you are not happy with the funding of the health care

Respondent: Yes because the health care funding should be paramount in our plan for Uganda but when you see allocations given to health centre settings, it is very low yet there are very many diseases even propping in, others would need research, even medics themselves they are few and there would be need for recruitment of more staffs that there will be....at times these health workers are still doing this because they are already banned out, maybe you get yourself a loan in maternity for one week, that one is already ban out, you get yourself a loan within the department, you work from Monday to Friday, if they could give you enough fund so that we can at least if somebody has small number of people to care for, rather than pretending to be caring for 100 patients when you have done only 5, what good is on 5 patients, that is wasting time? So if they can put more money on health, recruit more staffs in all these facilities and motivate them so that they like their work, at least there would be some improvement

Interviewer: So what do you feel, ok the funding, what good.....

Respondent: For rheumatic, I don't know how their funding are because if they were funded well, if their project is funded well then everything will be running smoothly because its funds

that makes, if its funded well, the programs will run smoothly, that one I don't have much to talk about because I don't know about the funding

Interviewer: Ok then, what about the health workers, are you happy with the numbers, the qualifications and then the quality of care that they are giving?

Respondent : One, they are few, the medical worker are very few, not that they are not trained but they are not employed, there are many health workers who are trained outside rather than those ones who are employed by the government and there are health workers who have passed on but they are even not replaced and you hear them talking of staff sealing and we don't understand, for me I don't understand what they say by staff sealing because the number of patients are increasing every now and then and there would be need for them to put more health workers, sensitise them, recruit more health workers, do more orientations because others have stayed outside for so long without working, even most of them have lost what they have learnt, so they are supposed to be brought back and do some refresher courses for them, so that they pick up and begin, that is why there is a lot of fake work in Uganda, most of the health workers come out of school,yeah,they have no experience, they go and open up clinics, they open up their drug shops, they want money but now they want money but in a wrong way, so they keep running around doing every fake things they feel like or they are trying to look for means of living because the government has failed to hire them, you! That is also one of them laughs.....both laughs because you can't just study and just stay seated at home yes and more so paid fees

Interviewer: Ok, what about the quality of care

Respondent: The quality of care, there is a lot of hindrances in the quality of care

Interviewer: Yes

Respondent: One, knowledge because there is that challenge I have seen in my practice, if we were together with you in class, we come out to work, we are different just because we have not put what we have learnt into practice, you have to marry what you have learnt into practice, you have to marry what you have learnt and ransomed together, that is when you have quality of care, with that knowledge being put in practice, but why our quality of care is not good. You get somebody who has a lot of knowledge but has never bothered to put it practically and when it comes to handling of patients, they are not competent, that one also hinders the care of our patient, they don't get a holistic approach because the medical worker is 100, I can say 99 or

98 %,most of them I would say like 50% down wards because knowledge they have but practice they don't have, then secondly depending also on the incorporation of the ministry of education and ministry of health into the training, it makes those other ones who are trained by ministry those days, those ones also under looks them to be those ones who are not knowledgeable, so there is that gap

Interviewer: So previously you were trained by.....

Respondent: Ministry of health but now the ministry of education has propped in, it's like the ministry of health gave them some portion and the ministry of education is over ridding the ministry of health in training so that one brings a lot of things, the student's feel they are for ministry of education, these ones were trained by the ministry of health so there is that gap

Interviewer: So what is the difference, those ones trained by ministry of education, are they more of a theory bit

Respondent: Yes

Interviewer: Others of a practical bit

Respondent: Yes, for them they know more of the knowledge other than the theory so they don't bother coming to practice and secondly their number, the number is bulky that training them is not easy because by then, they used to restrict the number of personnels being trained and they make sure you know what you are doing, when you are coming out, third year, they can leave you in the ward alone to run but these days they dodge work, they only like to pass their exams full stop, they don't mind so much about ransume,so that is the challenge.

Interviewer: Ok, quite interesting...both laughs. And then as a health worker, what motivates you to go on working?

Respondent: What motivates me is this work is not, you take it maybe the work you got because you are bright, you are whatever but for me as a nurse in a profession, I know it's God's work, I have been chosen to serve God's people with or without money I have to help God's people and I know God will reward me, so when I come, I know am working for God's people and the bible says if you are working you have to work like you are working for God not or human beings. Though there is a lot of work load but I still push on with the help of God almighty

Interviewer: That is nice

Respondent: Yes

Interviewer: And then do you really see that there is enough medication in the hospital like bendofin, heart failure drugs and all that

Respondent: At the moment I can say no because I see these patients at times they buy, maybe under the program of RHD, if they put some drugs there will be consistency

Interviewer: Ok, what of the general population?

Respondent: For the general no because at times they just come for prescription, they prescribe for them, they tell them to go and buy the drugs, we don't have and if somebody has no money, he is just going with the prescription, I went to the hospital, there is no drugs and I don't have the money, then the patient will not get any help at all

Interviewer: what about the diagnostic?

Respondent: The diagnostic?

Interviewer: Like echo

Respondent: But am just saying one year back, I called lira hospital blessed because when we did that bone on echo and they supplied us with those small echo machines and this scan, that one has helped us so much in diagnostic and I feel grateful

Interviewer: ok

Respondent: Yes

Interviewer: So what do you think the hospital hasn't done well In terms of medication?

Respondent: That one is not the hospital, I could just blame it in our budget, the Uganda budget. If they budget what is not enough for the ministry of health, definitely the drugs will keep lacking, so if they can improve on the budget for the ministry and a good portion is put on drugs, definitely the whatever, the drugs will be consistent and our patients will have their drugs consistently

Interviewer: So our problems stems from the ministry of health? Ok

Respondent: Yes

Interviewer: And then are you happy about you record system, records department?

Respondent: In the whole hospital or where I work

Interviewer: In the whole hospital, the inpatient, the outpatient, the registers and all that. Like let's say I wanted to get the total number of RHD patients, is it possible that it's being captured?

Respondent: I can't say no or yes, am just saying it's within because from my experience and the time I have worked, there are many patients who are not captured and more now with the setting of our hospital, we have the OPD on the other side where you are supposed to get the number. there are times when they are seen and they disappear or diagnose from here, You send them to go and get the number from the other side and they just vanish, so for me I feel the record is so improper because if we are in one setting now like maybe I think maybe it will improve when that complex building will come in. when we have the OPD with everything in it but if we are still sending them to akiibua its distanthiiiiii up to there, the patient will just vanish on the way

Interviewer: Ok

Respondent: Yes

Interviewer: Let's say like in your department, when I come there and I look into your registers and I want to see the number of RHD patients

Respondent: You will get them, you will get them

Interviewer: Ok

Respondent; Yes

Interviewer: and it's easy for me to actually trace them?

Respondent: Yes, yes

Interviewer: So what else don't you like about your record system?

Respondent: One, in the hospital, in the record system, the records system is good but my fear is capturing those patients because if the OPD, take in for example, a patient comes in emergency and has been managed in emergency and has been put in ward but before the patient goes to the ward, the patient is supposed to have a number, or the patient has recovered, the patient is supposed to get the number, so there is that possibility of the patient vanishing between emergency to the OPD, they can decide to pick their medical form pretending they are going for the number and they go home or they go somewhere else because they know already

the drugs has been prescribed, why do I have to waste time to go to that distance again and more so am sick and others without attendants

Interviewer: Meaning they are losing patients in between

Respondent: Yes, that is what I see

Interviewer: ok

Respondent: Yes

Interviewer: Anything else you don't like about the record system?

Respondent: For me I feel they have to recruit even more record workers almost in every department like emergency, they should be having a record personnel to capture these so that they don't go and vanish on the way, at least if they were captured within there, it would be nice because I see it's only the very sick patients that remains in the ward but those ones recovering, they go away without the number which means **our** say 100% but there is some problem with it

Interviewer: ok then you have talked about dislike, what do you like about the record system, the good things that they may have done

Respondent: They have a good reception, when I enter their, the records whatever, that communication centre, they have good settings, their chairs are nice, they are interesting in what they are doing, i think they love their work too and I always see them when they are looking for their quarterly reports and monthly reports, so I feel they are also doing, they are doing enough

Interviewer: Ok

Respondent: Yes

Interviewer: Do we have guidelines and protocols for RHD care?

Respondent: Protocols?

Interviewer: Yes

Respondent: Yes they are supposed to be there

Interviewer; But like have you ever seen one, like do they exist actually here

Respondent: No, they are supposed to be there but I have not seen one here

Interviewer: Ok, including referral pathways,

Respondent: We don't have the referral pathways, maybe I have not seen but I feel it's there because you can't see a patient and you don't know where to refer them, it has to be there

Interviewer: So generally about the patient outcomes, do you think that they get the care that they need or not especially surgery?

Respondent: The surgery?

Interviewer: The patient in the

Respondent: RHD patients?

Interviewer: Yes

Respondent: I think that they get what they need but not everybody is a beneficiary because its sponsor, it is sponsor, it depends now on those ones sponsoring, and how they are going to select these patients because you can sort them out, you send them to be accessed by those ones are going to sponsor them and it will depend on their choice, you may think this one is better, they would rather work on this but if they have decided to pick on the other ones, you have nothing to do

Interviewer: Ok

Respondent: Yes

Interviewer: So their surgeries depends on.....

Respondent: Yes, one getting a sponsor

Interviewer: Ok

Respondent: Yes

Interviewer: So why is it so?

Respondent: Why is like that, like they are unable to afford the care,one, it's very expensive and our patients are not in position to get the care, then secondly, it's a specialised area and getting specialist for those areas is not easy, that is why I feel our patients are not in the position to get the care and I find this research because at least it has put us somewhere, we have some

hope somewhere that at least they can screen the patients, they can diagnose the patients, those ones who need surgery are also sorted out and now they choose according to the donors

Interviewer: And then, do you have any patient safety and quality of care concerns?

Respondent: Pardon

Interviewer: Any quality of care concerns or patients safety concerns

Respondent: Patients of RHD?

Interviewer: Ok now this one is in general, any concerns, special concerns that you see or quality of care concerns like do you feel that they are getting the right quality of care needed

Respondent: Yes, people are trying, people are trying amidst a lot of things which are missing and drugs not being available, still we try as medics to do what is needful, or we can do at least to make them come out of their problem or to sensitise them about their conditions and also to see way forward, if others need referrals, other who needs other investigations still they try to have some care, good care also

Interviewer: Ok

Respondent: Yes

Interviewer: And do you think that there are prevented deaths that happened in the hospital

Respondent: Yes

Interviewer: Why, like in what circumstances

Respondent: Like let me say somebody has come in an asthmatic attack and if the patient has not been pushed in the hospital, definitely that patient will die just due to asthmatic stress, so I feel there is good care because if they come in that status, asthmatic attack, definitely they are going to be managed and the patient will come out of it

Interviewer: What of now, let's say the patient who is already in the hospital, do you feel that there are some patients who are dying when they were actually not supposed to have died in the hospital

Respondent: Yes, one, I had talked about knowledge deficit, if somebody who handling the patient is not aware of this patient's condition, like in a heart disease, you are supposed to withhold fluids but the patient may be decimic and somebody who is in the ward has not seen

the other part of it, in fact the patient will flee which means you have shortened the lifespan which is not supposed to be like that so it's always about knowledge deficit and you experience in managing this patient generally

Interviewer: Ok

Respondent: Yes

Interviewer: And do you think this is happening a lot in the hospital?

Respondent : Once in a while, when you get somebody who is not knowledgeable because this is a training hospital, I can't deny it wholesomely because you get somebody who is a student or whatever, would be rushing to do something in an attempt to save life but on the other hand he is killing the patient

Interviewer: Ok

Respondent: Yes

Interviewer: Ok and then do you think patients are dying in the community without presenting in the hospital

Respondent: Yes, very many

Interviewer; so why do you think they are dying without coming to the hospital?

Respondent: One, the attitude, people have wrong attitudes about the hospital, Misconception, they believe that they are being charmed it does not need medical treatment. People are not interested, attitude, they are not willing to bring them to the hospital, even money issues, times, they bring them to the hospital but even some body to care for them is not there, they just come and abandon them in the hospital

Interviewer: OK

Respondent: Yes

Interviewer: Ok, then in your opinion, could you give me one or two most important things ministry of health should do to improve outcomes, patient outcomes

Respondent: One, the ministry is supposed to revise laws and whatever governing the hospital and health care settings.They have to pass all through those things because there are those laws which they put long time which is not complying now because when they talk of staff sealing,

what do you mean by staff scaling when the number of patients are over whelming the staff, which is those ones they are supposed to at least look into it and they raise the number of staffs per the ratio of the patient, per staff. That is one thing the ministry of health should do, then secondly the ministry of health should learn to distribute specialists evenly in the whole country because when you see, there are only specialist around central and western and maybe some few in eastern but up country almost nothing hence making health care working as it's not supposed to because it; like a referral, how can you refer a patient to a setting which is not having a physician? No surgeon, no paediatrician, no gynaecologist, it's just like we are in un health centre setting, so the ministry of health should learn to distribute these specialists evenly in the whole country and motivate them also to stay in hard to reach areas because they don't like hard to reach like north

Interviewer: laughs

Respondent: Yes

Interviewer: Alright, anything else you want to add on?

Respondent: I feel they should like the ministry of health should also have a program like to extend the care for like heart diseases. If they could get a specialist also on heart disease and they put them, if they could train more and they put like one, one on every hospital, it would also be so good to help in the referral system rather than us screening from here, sending to them, that person would just screen everything for them, **the** post for surgeries or the other things

Interviewer: Ok

Respondent: Yes

Interviewer: Anything else

Respondent: I think that is all I can say

Interviewer: Alright, thank you so much for giving us your time and participating and I hope the ideas you have given us will really help us in improving the care for the RHD patients in future, thank you

Respondent: You are welcome

Participant ID	HW 012 - Lira
Age	■
Date	8th Jan /2019
Venue	LRRH
Interviewer	

Thank you so much today is the 8th January 2019 and the interview is being conducted in Lira regional referral hospital, family planning unit, in the doctor’s office. The study is mainly to determine how best we can provide care to RHD patients. We don’t have any right or wrong answers so feel free and be frank with all your answers and then all that we get here today is confidential, none of our reports will actually reflect your name or your identity so I would love you to be free with your answers. So we can start.

Respondent: ok

Interviewer: you can tell me about yourself, how old are you?

Respondent: I am [redacted]

Interviewer: ■

Respondent: yeah

Interviewer: And what’s your qualification?

Respondent; I hold [redacted]
[redacted].

Interviewer: ok

Interviewer: so, where did you qualify from, where was your training done?

Respondent: [redacted]
[redacted]

Interviewer: ■

Respondent: yes

Interviewer: ok how long ago were you qualified?

Respondent: [REDACTED]

Interviewer: ok

Respondent: [REDACTED]

Interviewer: [REDACTED]

Respondent: [REDACTED]

Interviewer: [REDACTED]

Respondent: that was when I qualified

Interviewer: and how long have you been working here in LRRH?

Respondent: in [REDACTED]
[REDACTED]

? Laughs Ok meaning here you have been for more than...

Respondent: [REDACTED]

Interviewer: [REDACTED]

Respondent: [REDACTED]

Interviewer: laughs... so which kind of patients do you usually see? Which are the commonest illnesses that you meet in your day today work?

m.... since iam not a specialist, we attend to all sorts of patients that we have around this region ranging from malaria, pneumonia and tuberculosis, diarrheal diseases, STIs, the rheumatic fever we are talking about, suspected cases and others, quite many, including injuries...

Interviewer: Accidents...

Respondent: accidents

Interviewer: so do you see like a specific age group or you cut across

Respondent: as I had said that iam not a specialist, we keep rotating

Interviewer: ok

Respondent: today you are attending to children, or this month you are attending to children, the other time you are attending to women, you can go to male, like that.

Interviewer: ok...so you kind of meet every group?

Respondent: you meet all sorts of patients

Interviewer: ok ...so during your school time, did you receive any specific training on rheumatic heart disease?

Respondent: yes, within the training, you know the training is broad

Respondent: and it's supposed to cover everything, and of course rheumatic heart disease, ok let's say rheumatic fever, start from rheumatic fever of course rheumatic heart disease will now come in as a complication of..... streptococcal bacterial infection, so all those bacterial infections were covered

Interviewer: ok and then you are aware of the link between sore throat and rheumatic heart disease right

Respondent: yes, yes yes

Interviewer: what do you know about it?

Respondent: I know the sore throat is a step.... a beta hemolytic streptococcal infection which is more common around the throat...although not only throat, even on the skin of the patient, it can affect any part of the body. But when it attacks the throat and the patient develops antibodies against the infections, and then the antibodies will clear the bacterial infection, but as time goes on the body will recognize the antibodies it had produced as foreign again it begins reacting to the antibodies it had produced against the beta hemolytic streptococcal infection so, it is the antigen antibody reaction then which becomes a problem not only in the heart it can be in the brain, can be in the heart, can be at the joints it can be in the kidneys, those target organs, and if it affects the heart then we have rheumatic heart disease, when it is the joints then we have rheumatic arthritis

Interviewer: ok

Respondent: yes,

Interviewer: wow

Respondent: that's what I still remember when it's in the brain then many of our patients present with rheumatic fever disease, they present with symptoms related to rheumatic fevers

Respondent: yes

Interviewer: ok, let's move a bit aback, I mean slightly, other than the training you received from school, did you receive any other trainings on rheumatic heart disease since graduation?

Respondent: no, I told you, iam a teacher, I am a health tutor by training, so being a health tutor by training, I teach, and because I am teaching medicine, I am a teacher of medicine, because iam teaching my students then I would say I am training, I am being trained time and again, all yearly, those we shall have to cover...

Interviewer: you keep yourself updated all the time

Respondent: yes, yes, we keep ourselves updated

Interviewer: ok... and then in the patients you see, how many patients of RHD do you see per day?

Respondent: depending on the location, right now you have found me in family planning, when iam here in family planning, I may end up not attending to any of the patients of RHD, but if I am in the general out patient, yes, chances that I will see, especially in children, chances that I would attend to more than 3,

Interviewer: in a day?

Respondent: suspected, suspected cases, not real ones, suspected cases of rheumatic heart disease are many, because it is almost, I would say it is common

Interviewer: ok alright... and then, the patients you meet, are they only out patients or you also see in patients?

Respondent: out- patient patients

Interviewer: ok so we can go back now, you had actually.... told me what causes Rheumatic heart disease...

Respondent: yes, yes, I talked about beta hemolytic streptococcal infection as being the prime cause

Interviewer: ok... what were you told that can be done to prevent rheumatic heart disease?

Respondent: I would think about health education, people should be well educated about rheumatic heart disease, but of course when they have the information they will not move around in the villages, this issue of I have been poisoned, and because I have been poisoned, then they go to those traditional healers and if they come to the health facility and we diagnose the infections in the throat, treat it early, then we will have prevented the production of the antibodies, we shall have prevented the production of antibodies which the body would react to in the later stage, so early diagnosis, early treatment, health education is paramount in the prevention of rheumatic heart disease

Interviewer: then, which treatment options were you taught about for rheumatic heart disease?

Respondent ... RHD is supposed to have long acting antibiotics especially the penicillins of course beta hemolytic streptococcus tend to respond better to penicillin. And ...when someone has already developed RHD, in the process of developing rheumatic heart disease, one of the things that we need to prevent seriously is the subsequent attack of beta hemolytic streptococcal infection, therefore we give them long acting penicillins majorly things like benzathine which takes little longer in the body and some steroids where possible to neutralize the antigen antibody fights that I was talking about

Interviewer: ok... any other treatment options that you know of?

Respondent apart from... apart from penicillins?

Interviewer: yes

Respondent: yes, surgical maneuver can come in in case of some pathology in the heart, although it is not performed in this facility, but maybe if referred to other places, yes, in case it has already destroyed the valves and then it would require valve replacement, which is fairly expensive

Interviewer: yeah and may not be available in the facility, or even in the country ok...and then what is your understanding of the long-term prognosis of rheumatic heart disease?

Respondent: the prognosis depends on... the long-term prognosis now will depend on the magnitude of the damage, if the intervention got the patient when there was no serious damage, then there would be good prognosis.

Interviewer: ok

Respondent..... but if there was destruction caused by the antigen antibody reaction, then the prognosis would be poor, the person would present with full blowndestroyed say valves of the heart and might even go into heart failure

Interviewer: ok

Respondent: and we may even lose that such a patient as a result

Interviewer: true

Respondent: and we have lost many

Interviewer: ok... do you recall the last patient you saw with rheumatic heart disease?

Respondent: actually, I am even expecting one today

Interviewer: ahhh.... maybe you could tell me briefly about the person you were expecting, how they presented to you, maybe the first time...

Respondent: ah...one in their history, actually, they tend to forget about the throat infection, but when you begin asking them about it, they will say yes that has been my problem, I had recurrent throat infections, it was treated, they talked of chopping off the tonsils but it was expensive so, there would be that history of sore throat or recurrent sore throat with associated fevers then when you look through the throat of course with our setting here, of course you see that people have already tampered with the uvula, because people assume that when there is pain, whether there is sores in the throat, the hanging structure seen could be the offending structure, therefore they move in and chop the uvula off and in case, in many cases after chopping off the uvula, they also give antibiotics, since the infection is self-limiting, within 3 days you expect it to clear, within 3 days they will assume that it has cleared because they have chopped off the uvula therefore, the practice around here is that when there is a problem, the uvula should be chopped off, which is actually not the case, so thereafter it will take some time and they will come with features related to heart failure of course, those are now the late complications by the time they are coming out with structures associated with heart failure so when you complain about palpitations, easy fatigability, sometimes swelling of the lower limbs or weakness of the joints, sometimes when you listen to the chest you will have those irregular heart actions and sometimes when you send for investigation, the investigation will reveal that they have issues with the heart, but going backwards looking at the history the patient gave me, then you will know that this one came as a complication of the sore throat that patient had and if that is the case, then it will be more of rheumatic heart disease

Interviewer: ok... quite interesting. So, on average, what is the average age of the patients you see, those who present with rheumatic heart disease?

Respondent: they are not, majorly they are not adults, it's more common among children and more common among girls than boys that's my experience

Interviewer: or it's the girls who have good health seeking behavior...

Respondent: aha.....yes, possibly, possibly possibly the girls complain more easily than the boys but more girls are brought to the facility than the boys

Interviewer: so...this.....

Respondent: about 7 years

Interviewer: 7years?

Respondent: yes

Interviewer: so, these ones who come, are they in school, do they report being in school or they are out of school, are they school drop outs?

Respondent: many of them are in schools, many of them are in schools

Interviewer: ok....and adults? Any adults who show up with RHD?

Respondent: adults rarely report, when you see an adult coming, then that person is already in late stage

Interviewer: ok...with complications

Respondent: With serious complications but as I said, when you go backwards, you will realize that this person was not well managed at the initial stages of the infection.

Interviewer: ok. So, when you try to talk to them, are they really aware of the link between sore throat, rheumatic fever and RHD?

Respondent: no, they are no aware, they are not aware,

Interviewer: ok...

Respondent: actually, they are surprised, especially the adults, they are surprised, when you begin telling them of the sore throat, of course, they will not benefit much from your education, because already

by the time they are coming to the facility, they will be having the complications, but they would be surprised and when you talk about if this was handled earlier, well, you will not have gone into this, then they will regret, say if I had known then I would have acted

Interviewer: meaning they have knowledge gap

Respondent ... there is an issue of knowledge about it

Interviewer: so, when they present to you, what sorts of symptoms do they describe?

Respondent: of course, palpitations, easy fatigability, difficulty in lying on the left side

Interviewer: ok

Respondent: and...even lying flat sometimes is their problem, most of them will be seated... but of course as I had said most of them would be the late cases reporting to the facility..... phone rings...hmmm so...yes

Interviewer: do any of them ever tell you about other symptoms like joint pains?

Respondent: joint pains yes...joint pains, joint pains is there especially in adults, especially in adults...ok, joint pain and swelling and partial loss of function is more in adults

Interviewer: ok

Respondent: yes....is more in adults

Interviewer: and not in children?

Respondent: no, it's fairly rare in children you know when people tend to associate When they come with joint pain, severe joint pain is more common among Sickler's so, you find people moving them more to investigating sickle cell, of course sickle cell is also more common so sometimes sickle cell and rheumatic heart disease is mimic

Interviewer: do you think we are missing out children with rheumatic fever being directed to sickle cell clinic?

Respondent: yes ... that's what I think. That is another thing I think of course, those children, those ones with sickle cell disease have low immunity, and have higher chances of even developing rheumatic heart disease...

Interviewer: ok

Respondent: and in such situations, sickle cell will be blamed for causing the problem when actually the problem is rheumatic heart disease

Interviewer: have you met anyone with both

Respondent: yes, they are many

Interviewer: many?

Respondent: yes, I wish you could check through the sickle cell children? In the sickle cell clinic, you will discover that oh, our patients are here...ok, many of them are there.... phone rings again and requests to answer it ok...

Interviewer: so generally, what's good about the follow up? Is the follow up really good? And what about the adherence?

Respondent: follow up is not good, why? I said rheumatic fever is more among children, more common among children

Interviewer: ok

Respondent: and people tend to neglect children, if you tell a parent that you would want to see this child after 2 weeks, they will come when the child is badly off, they are never considered in most of the families so, follow up is ... is not very easy of course, the follow up in a hospital in many cases you would want the patient to come to the hospital but not the health workers following the patients to their homes so, may be one day if the strategy of follow up is changed, where people follow these people to their villages...then possibly, they would be attended to, but they would wait until when there is another serious attack has come, then they come to the facility so, they never follow their appointment dates the appointment dates are never followed

Interviewer: ok... is it because they are feeling well.....

Respondent: of course, yes, if the child is still playing about, or if someone is still doing well, they tend to forget, they think the whole thing is cleared.

Interviewer: ok. What of adherence, do they follow their prescribed medication? I was like, the treatment would prevent, preventive treatment where you would think of those long acting penicillins...

Respondent: ...yes, if it is too long, then they may not, they may not adhere to

Interviewer: ok. Then what sorts of barriers do they commonly state to you in getting the care they need...challenges they face?

Respondent In the first-place lack of information because they lack the information, they will not go to the health facility or to a trained health worker to make the correct diagnosis and treatment that is one, then two, sometimes distance assuming somebody is in Aromo, and is not interested in going to aromo health center because people are saying there are no drugs in aromo health center, because our people believe in drugs that when they go to the health center, they must get drugs

Interviewer: ok

Respondent: they don't believe in this information, the prescription that we make but they would want to get the drugs in the health facility, and if there are no drugs they will go to the private facility because there are drugs there. Unfortunately, many of the private places are not managed by professionals you will find a facility well stocked with drugs but managed by a nursing assistant see that? So, the nursing assistant may not be in the capacity of making the correct diagnosis and prescription, the correct prescription

Interviewer: ok

Respondent: so, that could be an issue, distance coupled with lack of information that they have poverty coming in, coz they don't have money to travel that distance from aromo possibly to lira hospital or if those areas of my village in oyam, otwal, is far away moving from that place to maybe atapara it requires resources so, it's sometimes difficult for them

Interviewer: ok

Respondent: they wait until there are serious complications and actually, when they are going to the hospital, they go for admission

Interviewer: laughs.... So, they wait when they are badly off

Respondent: when they are badly off

Interviewer: what about you, which barriers do you face?

Respondent: in the health facility? In our facility?

Interviewer: yes

Respondent: one I talked about ah... ok let me start with personnel,

Interviewer: yes

Respondent: that we have very few well trained clinicians or experienced clinicians... the outpatient, our outpatient right now I think should be having like 3 clinical officers

Interviewer: ok

Respondent: and if one is possibly sick and maybe another one is on leave, then you would see that there is only one person left at the station meaning that the care that our patient may not be adequate

Interviewer: ok... quality of care...

Respondent: the quality of care will be compromised the time spent, of course for you to get a proper diagnosis, you need to have time for the patient, take adequate history, do all your physical examinations, where possible order relevant investigations, then you conclude

Interviewer: ok

Respondent: but the pressure there, sometimes you would find some few history written and then somebody would move straight to prescription, which is not the order which is not how things should be done

Interviewer: ok

Respondent: but... that is one, two. As I mentioned, I think I mentioned it yesterday, that we have, sometimes we get volunteers but a volunteer, someone who is not paid for the activities they are doing can also have his or her special interests of being within the facility. One he is difficult to supervise two, because of the other interest, that hidden interest, it is difficult, so those are some of the things. And then two, drugs.....

Interviewer: ok

Respondent: that in many occasions....

Interviewer: so, should I say lack of motivation for the volunteers?

Respondent: yes, yes, lack of motivation.....

Interviewer: or for the health workers?

Respondent: the health workers are getting their salary but the volunteers are there for nothing

Interviewer: they are not paid anything?

Respondent: 100% they are there, they are not getting anything completely,

Interviewer: they are not getting anything? I thought the hospital is supposed to provide something?

Respondent: that is administrative but they are not getting anything so, it makes it a little difficult....

Interviewer: ok

Respondent: to supervise them and to monitor some of their, ok their hidden interest is difficult then I was talking of shortage of drugs, you may wish to prescribe a drug or you can prescribe a drug and the drug is not supplied by the pharmacy, that we have.. Why, because there is a stock out, so that one interferes with adherence

Interviewer: ok

Respondent: and then the quality of care that you are offering to the patient, therefore, meaning that, meaning that your patient will come back with serious complications and investigations, investigations... the results of the investigations tend to take long

Interviewer: ok

Respondent: if you order for an investigation, you are thinking about rheumatic heart disease...and you would want investigations done, so that you maybe refer the patient to the respective places that they can get adequate care, two things, you may receive your patient back or you may not see your patient anymore

Interviewer: do they get lost on the way?

Respondent: they get lost on the way

Interviewer: due to the long waiting hours at the investigation point.....?

Respondent: that one I have not discovered yet, that one I have not discovered yet, but sometimes they also get lost on the way

Interviewer: ok

Respondent: then... if you have referred or you have admitted the patient **Respondent** sometimes we don't get any information about our patient

Interviewer: so, lack of feedback

Respondent: feedback about your patient

Interviewer: ok what else...?

Respondent: I think basically those are the ones

Interviewer: And then, ok now this is in your perspective, what sorts of barriers do you perceive that the patients face in the care that they need?

Respondent: one major problem that me as a person think of is health education

Interviewer: ok

Respondent: in the community. Health education is a major problem, we are going back, actually most of our patients are going back in the times of Albert Cook where when they fall sick, they do their things in the villages, they are going into those days of, someone has developed, because those days in the past in lango, in the past, if there was someone with a sore throat, they would pour water on an axe, then they would scoop it, the other one pouring on the other side the axe would be handled like this ... (demonstrates) then somebody pours water there and this patient must have to, must take this one which is dropping from the sharp edge of the axe and they say it would clear, it would treat very well

Interviewer: would it really work?

Respondent: so that was the action of the mind over the body...

Interviewer: laughs.... hmmm

Respondent: they would just play about with your mind so that you assume you are treated. so, our people are almost going back to those ancient methods of treatment, that's why you are seeing others coming, ok... am seeing almost 30% of our patients have lost their uvula so, there should be proper health education about sore throat

Interviewer: ok

Respondent: in case there is any sore throat, let us not have any body tampering with the mouth

Interviewer: laughs

Respondent: they should go to the health facility so that they are adequately treated, so that there is proper diagnosis and proper treatment, otherwise we shall continue receiving them at a late hour in the hospital or in the health facility so, to start with, I would think there must be adequate health education offered to the people

Interviewer: ok which other barriers do you think they face?

Respondent: I mentioned the distance....

Interviewer: this is in your view, what you think they go through

Respondent: another thing could be our attitude, some of us are not friendly to our clients, some of us are not friendly to our clients, we tend to ignore them and indeed, if someone comes to the hospital and I have not given him the proper attention he expects, sincerely, he will lose interest in getting services from the facility, goes back to the village and have it the other way, the traditional

Interviewer: that's why I was told mothers prefer traditional birth attendants

Respondent: yes, yes

Interviewer: because they are treated nicely

Respondent: yes, majorly it's our attitude towards our clients and patients, so maybe health workers must develop that customer care attitude they should recognize that they are our customers, they are the reason why we are here...

Interviewer: yeah

Respondent: and then treat them fairly because they are not the same, others are coming to the health facility for the first time, they have been in the villages so crossing to lira they would have a lot of fear and if they are mishandled then automatically, they would lose interest in getting care from the health facility so, attitude is another big challenge another big barrier

Interviewer: ok. Anything else?

Respondent: basically, I think I would mention that

Interviewer: ok. So, let's talk about the administration and leadership in the district, what do you think they have done well for you?

Respondent: Am happy to see this tent, the other tent, on our compound, which is managing rheumatic heart disease, iam also very happy to see some of the health facilities referring suspected cases of rheumatic heart diseases, however iam not happy with the reception of these people referred from the health facility because sometimes we don't give them, you know, those people in the community when they are referring, this is rheumatic heart disease, you must be managed in the hospital, there is a special clinic in that place which should be, which should handle this patient **so** am referring, then they will refer, so the person will come to the hospital knowing that I have a heart disease and this heart disease of mine will be handled by a specialist and I may even be admitted and treated very well and eventually I will not have this problem. Meaning that if we make the proper diagnosis, those people don't have investigative facilities so if we have done the investigation in this facility and we have discovered that this patient is not having the RHD that this person was talking about there should be a lot of counselling of this patient, so that the patient gets to understand that yes, those people also did good to refer me to the facility however iam lucky that I don't have the disease, iam having something else and I wish the unit could also move with this client referred and then look for whoever can attend to this person referred so that the patient gets the adequate care and goes back satisfied. it would be so good but what happens is, if it is not the disease, it is written on a piece paper, this is not a case of rheumatic heart disease, go to out patient

Interviewer: laughs

Respondent: and this one would get lost within the hospital, he or she has come from very far and may not know what else to do, so what will they do...back to the village, unsatisfied so, I would think there should be a mechanism or a linkage between the general service, the general service delivery and then rheumatic heart clinic, first receive everybody, do the screening, if it's not related to what you are handling, support that person, give the adequate counselling, after giving the adequate counselling, unless there are no counsellors but we have counsellors in this facility, look for a counsellor, counsel this person well, about the rheumatic heart disease and then the condition which this person is having so, by the time the person is going back home, he would really be very happy and may prolong the duration, the time of that person and improve on the health.

Interviewer: ok. So, what do you like about what the district has done, the leadership and the administration? I may talk about lira hospital, I do appreciate the idea of accepting this rheumatic heart

disease management on this compound and integrating it with other services that we have I wish to praise them for that I would also wish to congratulate or thank the donors who have offered some resources, to have these services within the facility to support our local people however, there is a lot more, so that we have these people coming for the services, there should be more time spent on sensitization so that we have the places, not even, I would wish that if there was a special place, not the tent, if there could be a designated room or house for the purpose and if they could look for ways of retaining the program because rheumatic heart disease is not about to end. It will still be there for years, meaning that the services will be demanded not for a shorter time but for....

Interviewer: a long period of time

Respondent: yes

Interviewer: ok

Respondent: so, people should be looking at how to retain the services so that it is always there. Then, I wish they could think of continuously training health workers, if they could continuously train health workers have in plan, that the health workers even in the health facility, in the hospital here and other places are trained and then supervised on the management of rheumatic heart disease, it would be so good

Interviewer: ok. That is with the administration?

Respondent: yes

Interviewer: so, they are not doing that?

Respondent: no

Interviewer: those are the things you feel they are not doing? Maybe you can just mention briefly what you the administration is not doing right and the leadership of the district, what you feel hasn't been done

Respondent: What has been done I think I mentioned it I talked about it

Interviewer: yes, what has been done, now we are looking at what you think should have been done and is not being done.

Respondent: the element of, the element of support of follow up

Interviewer: ok

Respondent: because if these patients are supposed to come back for review....

Respondent: and they are coming, there must be a mechanism of tracing the defaulter, which is not there, I guess is not in place, so there should be a mechanism of tracing the defaulters....

Interviewer: ok

Respondent... so that they are comprehensively treated and they get cured. I think that is what I would talk about

Interviewer: ok. Are you happy about the funding of healthcare in general?

Respondent: no

Interviewer: laughs.... what of RHD?

Respondent: I don't know the funding of... I don't know, I don't know, I don't know what the implementers are experiencing, the implementers of this program, I don't know what they are experiencing, but may be if I can see from your body then I would think that you people are doing well

Interviewer: laughs.....

Respondent: laughs...however generally

Interviewer: what of generally funding for health care?

Respondent: generally funding for health care is not adequate if it was adequate, we would be having specialized machines like a CT scan in general in regional referral hospitals we could be having MRIs in general in the hospitals, but now where do we get them? In private places in Kampala very expensive, and they would help in the diagnosis of some of those cases easily see that? So, the funding, look we are talking about motivation we are talking about staffing, if there was proper funding then we would be having enough staff in the health facility, but usually what do they say? The wage bill cannot allow, and if the wage bill cannot allow, what does it mean, there is no money! So there should be, to me there should be enough funding so that the staffing level is raised....

Interviewer: so, meaning the staff level is low?

Respondent: very low... yes, very low

Interviewer: ok. They are low but you have the right qualification

Respondent: yes... we have the right qualification, but as I had mentioned, that now we are getting...ok the right qualification, yes we are getting volunteers who are not motivated, and the facility cannot motivate them why? Because there is no money, and there is no plan for them.

Interviewer: so how is the quality of care offered?

Respondent: ahh... I had mentioned that the quality of care is compromised

Interviewer: because of the few staff?

Respondent: because of the few staff

Interviewer: how would you talk of the waiting time?

Respondent: prolonged

Interviewer: ok. On average, how many hours would a patient have to wait?

Respondent: sometimes even more than 2 hours

Interviewer: more than 2 hours? Ok. So as a health worker, what motivates you?

Respondent: first of all, being a health worker is my motivation, I'm not a health worker by chance I'm a health worker by choice....

Interviewer: ok

Respondent: and I love to be what I am. And if I have treated you, when you are badly off and tomorrow, I see you cured, I get motivated

Interviewer: other than that, what makes you carry on?

Respondent: ahh.....the finances we talk about is just a source or a means to motivation, because I would want to come to the hospital, I'm a health worker I live, my home is about 5km away I would want to a place where I do offer my services and I feel happy about it, but coming from my home to the health facility requires resources, requires money therefore, the money should be given to me by the facility, but what do we receive? What we receive is not sufficient, although you have been hearing that there is some increment. But the increment of salaries that usually occur also has challenges, because by the time salaries were increased, even the prices of everything shot up so, everything is balanced again, you see

that? Everything is balanced again if fuel was at 2500, by the time they are increasing the salary, it has now gone to 4000 actually 4300 now if I was using a fuel from my home to this place, I would put in fuel of like 10000 and 10000 or 15000 would take me for like 3 days but now I'm using 30 see that? So, it has balanced everything

Interviewer: so, there is actually no increment....

Respondent: there is no increment, there is no increment that is how iam looking at it there is no increment. Meat by then, meat was 8000, by the time salaries increased, now it is 10 and 12

Interviewer: laughs,

Respondent: its 10 and 12

Interviewer: laughs.... did they decide to increase their prices because your salaries were raised?

Respondent: laughs... so, if the salary is increased by about 100% and then they have raised the cost of meat by 30%, the cost of fuel by..... like.....

Interviewer: almost 50%?

Respondent: by about 50%, look at that, you almost see like there is no increment. Pay as you earn has also taken most of the money they say ok, we shall give you 3 million, we shall give you 2.2, 3 million you end up getting 2.2m, 800 pay as you earn, ahh... yes, that's what it is, you end up getting 2.2. 2.2 If you are an old man like some of us, who have now children at the university, what do you remain with?

Interviewer: almost nothing

Respondent: actually negatives

Interviewer: laughs

Respondent: laughs. you go into borrowing, and those bor...actually the element of borrowing is a big problem in health services, I mean in the civil services because almost everyone in government service has a heavy loan to pay, and the loan is taking already more than ok about half of the salary of almost everyone is taking almost half of that salary, and if a half is taken by bank, half of what that person is getting is taken by bank, the other half remaining cannot do the basics, therefore you find people running up and down to do other things so that the family can also survive. And when they are doing this they are doing this at the expense of service delivery, and there is no way you will say no, please don't do this of

course maybe part of the money that the person took a loan for was paying school fees because whatever he has or whatever he is getting from the facility cannot satisfy the needs

Interviewer: yeah

Respondent: so, he would go in for the loan and then there after is running up and down to fill in for some of the gaps. So, it makes supervision very difficult

Interviewer: true

Respondent: that's when, that's when the element of volunteers taking over office, you see a volunteer, the real person supposed to do the work requests the volunteer , please am still moving out, handle my patients, then the volunteer will do the reverse of what is expected. You see that?

Interviewer: yeah

Respondent: but if what was given to the civil servant was fairly good, they could cover the basics of the civil servant, then people would have more time at their places of work and then offer their services.

Interviewer: true

Respondent: you are lucky you are not in civil service...laughs

Interviewer: laughs... but I will soon join

Respondent: please come... there is advert

Interviewer: ok

Respondent: they posted yesterday

Interviewer: ok. What about medication, do you think we have enough medication like benzathine, heart failure drugs and diagnostics in the hospital?

Respondent: many times, they are out of stock, many times they are out of stock

Interviewer: ok

Respondent: they will say very little was brought

Interviewer: so most of the time they are out of stock?

Respondent: most times they are out of stock

Interviewer: ok. Then why is it so, why is it always out of stock? Is it because the budget is small?

Respondent: I think the pharmacist would answer some of those,

Interviewer: ok

Respondent: I may not be in position, but sometimes when you ask them, others will say, you know, we order for the drugs but what is brought is not our order, we had ordered for this, look at the order book, we ordered for this but what is brought was this, so we go by what has been brought

Interviewer: ok

Respondent: I think they know the reason why some of those happen the way it is happening

Interviewer: what of the records system, do you think it is doing well?

Respondent; hmm.... records, yes, record have greatly improved, they have greatly improved, both out patient records and in-patient records

Interviewer: ok

Respondent: HMIS has greatly improved

Interviewer: ok so, what have they done well?

Respondent: in the first place, record officers are many, they are many, and because they are so many, their quality of service is improved

Interviewer: ok

Respondent: they do their work with little stress, and because they do their work with little stress, they offer quality services

Interviewer: ok. That's nice. Then what do you think they haven't done well?

Respondent: what they haven't done well, the records officers? The record people?

Interviewer: yes

Respondent: maybe weekend coverage is an issue, weekend coverage is a big issue

Respondent: because sometimes you would find the stores, I mean the records non-functional over the weekends, if they could only improve on that it would be so fine,

Interviewer: ok

Respondent: and many times, shortages of forms can also deter their activities, ok it is not their making it could be institutional

Interviewer: ok. If I went to their offices, would I get like registers for acute rheumatic fever or RHD patients?

Respondent: that is not their problem that is not their problem that is the same thing iam complaining about sexual gender-based violence ah... some diseases are grouped under others. I have not checked the register yet, but there are many diseases that are grouped under others and then you know others are never specific so, you may want to see a specific disease and they say ...ah... that one is under others, and the others will be so many I was giving an example of sexual gender-based violence, they would just call it domestic violence but we have rape, we have defilement, physical injuries, so we would want those categories spelt out. So, the same way, maybe, I said I haven't checked the register yet,

Interviewer: ok

Respondent: maybe you will find rheumatic heart disease also put under others

Interviewer: under others... so actually you won't be able to quantify the total number of patients seen here with rheumatic heart disease

Respondent: yes

Interviewer: ok. What about guidelines and protocols on rheumatic heart disease, do they exist in the hospital?

Respondent: I haven't seen any

Interviewer: you haven't seen any? Wow. We have had so much about local systems and health systems and all that. But now let's look at perception of patient outcomes. Generally, do you think that these RHD patients are getting the care that they need? Especially surgery?

Respondent: no

Interviewer: why do you think so?

Respondent: of course, when there is surgery you would think of referral to Mulago, heart institute and referral to Mulago heart institute has so many things attached, one, you would need maybe transport...

Interviewer: ok

Respondent: and transport from the hospital may require fuel which may not be available then 2, the upkeep on the other side will also require money, so in many cases if a patient is having a serious heart disease, RHD, and you think the patient may benefit from services outside a place like lira hospital they go back home, they condemn the patient, the patient is supposed to go to Mulago, we don't have the resources, what do we do? Back home

Interviewer: that is really sad. Are you aware of any patient safety and quality of care concerns?

Respondent: pardon

Interviewer: patient safety and quality of care concerns?

Respondent: yes, yes, I'm aware

Interviewer: ... like which ones?

Respondent: we have patients' rights and ...which we are supposed to observe... we also have health worker responsibilities to match those rights and we are supposed to as health workers we are mandated to handle those issues of rights of our patients

Interviewer: ok

Respondent: one they have right to information, we must give them correct information, they have right to correct treatment and we are supposed to offer the proper treatment that they are supposed to, that they demand and it is our responsibility

Interviewer: ok

Respondent:when we are in this health facility to fulfill all those and others, there are a number of things entailing the rights of patients

Interviewer: ok

Respondent: which is documented in the patient charter, I think we have it in this hospital, patient charters are there

Interviewer: ok, so, do you think we are following them?

Respondent: I ... yes, some areas, yes, some areas has challenges

Interviewer: ok

Respondent: and the challenges, others are man-made, others institutional, others national issues see that?

Interviewer: ok. Do you think we have preventable deaths occurring in the hospital?

Respondent: yes

Interviewer: like which ones?

Respondent: maternal death

Interviewer: aha what do you think would be causing such?

Respondent: late reporting

Interviewer: by the staff?

Respondent: late reporting by the patient

Interviewer: oh...by the patient themselves

Respondent: the patient reporting late

Interviewer; ok

Respondent: or lack of what to use

Interviewer: in the hospital?

Respondent: in the hospital

Interviewer: ok. So, it's sometimes the hospitals.....

Respondent: supposing a patient has come, a mother had come with severe anemia and there is no blood in the facility, don't you think such a death would be prevented if there was blood?

Interviewer: yeah

Respondent: now we don't have a gynecologist in this hospital,

Respondent; supposing a mother comes to the hospital today with a serious complication, that requires the attention of the gynecologist, and the medical officer will say no I am unable to handle this, I needed the boss and the boss is not there, what would you expect? Death of this mother

Interviewer: yeah

Respondent: death of that mother. So that would have been a preventable death but because such a cadre that was supposed to manage that mother is not there, then the mother may die

Interviewer: ok

Respondent: because the mother wanted blood and there was no blood, the mother will die, we even had issues where we would lose children because there was no oxygen, but iam happy the hospital has now installed the oxygen plant with in the institution, but we had lost so many in the facility because there was no oxygen

Interviewer: that's sad

Respondent: yes... and yet those could have been preventable death

Interviewer: do you think we have patients dying in the community without presenting to the hospital

Respondent: yes

Interviewer: why?

Respondent: accessibility

Interviewer: to the hospital?

Respondent; to the hospital, you cannot access the hospital easily, by the way there is no...sometimes in 1998, 1999, 2000 and so on, there used to be, there used to be a radio call that were planted on the ambulances and the health institutions and they would coordinate say we have a serious patient, we have a very severely sick person we are bringing into the facility please prepare, by the time these people were reaching, the hospital you would find the hospital set or there was communication from the villages they were calling them what? I have forgotten, there were people in the villages that would hurry the patient to the health facility or call the facility and the facility would pick the patient from the village to the health facility and if they were unable to manage, then they would coordinate with the referral center and rush

the patient, but those things disappeared again. So, the linkage the coordination between the village, the smaller health facilities and referral centers is lost again

Respondent: is lost

Interviewer: ok

Respondent: so accessibility of services is not easy

Interviewer: ok

Respondent: and then the bureaucracy, you must first do this, first do this

Interviewer: like you must have a referral letter before coming here

Respondent: yes, there must be a referral letter. Then we are lucky we now have the casualty, emergency otherwise in the past, people would come and get lost within the hospital, come to the hospital with a man who is having obstructed, I mean intestinal obstruction, and the man will be taken to maternity, and maternity will say we don't admit men

Interviewer: laughs...ok

Respondent: go to the male ward, and then the man will be taken to medicine ward, he has intestinal obstruction, taken first to maternity, maternity would refer to medicine, medicine would say this is not our patient, maybe the person would even sleep there then the following day he is taken to his ward. Surgery

Interviewer: surgery

Respondent: and you think by the time they are taking him to surgery he is yet a human being?

Interviewer: no

Respondent: the whole gut is not there, so I'm happy that we now have casualty where everyone is would first be taken there and assessed, resuscitated then eventually forwarded to the rightful places

Interviewer: ok so, in your opinion, what are the 2 most important things ministry of health should do to improve outcomes?

Respondent: the things which should be done are....., we had talked about funding,

Interviewer: ok

Respondent: there must be increase in funding of health, in health

Interviewer: ok

Respondent: two, there should be improvement in recruitment of staff

Interviewer: ok

Respondent: three, they should think about infrastructure, remember a place like this hospital was built way back in 1928, when the population of this place was less than 1 million. I guess, because the population of the entire country was less than 5 million

Interviewer: yeah

Respondent: so, the population here could be less than a million, but we still have the structure for that population

Interviewer: laughs

Respondent: and then, you know, the staffing depends on the structures, the staffing of an institution like this one is looking at the existing structures

Interviewer: ok

Respondent: meaning that even if we are saying now, we have enough staffing for lira regional referral hospital that is not the required staffing to provide services to the population, the increased population

Interviewer: true

Respondent: so, there must be something done to relate the population and then the required health professionals, like if this is the population of lango sub region, about how many health workers , about how many cadres of these health workers do we need to take care of this population, there should be something done related to that, but not looking at structures of the facility per se otherwise we shall still have the shortages of staff we are talking about the burn out of the few staff within the facility because of the exploding numbers of patients and even the drugs, coz the drugs coz the drugs also they also look at the structures, if one day, people estimate the number of people who get services from the private facilities then join in the health facilities, in the government facilities, maybe take a half of those going to the health facilities, then we shall have more people seeking care from well-trained motivated health workers rather than moving here and there to delay care then eventually when they have failed from the

other side, they would have done many things one, they will have taken away the resources, say the resources those people have two, they will have delayed care, then finally they are referred to the health facility when they are dying so they will have lost everything, see that?

Interviewer: yeah

Respondent: or another thing, if RHD management that we have in the facility could also organize trainings for some of those people in the private facilities as well, so that we don't delay them, they do something for the patients, since others prefer going to them. It would be so good

Interviewer: ok. Anything else?

Respondent: apart from thanking you?

Interviewer: laughs

Respondent: and your patience?

Interviewer: ok

Respondent: I have loved your patience, thank you for checking on me

Interviewer: and thank you very much also for accepting to be a part of this

Respondent: you are welcome

Interviewer: sparing for your time

Respondent: its ok

Interviewer: yeah

Respondent: thank you so much

Interviewer: you are welcome.

Participant ID	HW 001 -Mbarara
Date	8 /Nov/2019

Interviewer: Thank you for allowing to speak to us. Just to remind you, there are no right or wrong answers; we just want your opinion and we just want to see how we can improve care for our RHD patients. I will just request you to be frank and share your opinions because the data we are collecting is confidential, and then I will just request you to be a little bit loud. Sometimes we fail to hear people on the . . . I have a big voice so I usually hear myself but sometimes I don't hear . . .

Respondent: the voice of the respondent?

Interviewer: Yeah, and mine is not as important as the voice of the respondent in the study.

Respondent: Okay.

Interviewer: So please tell me a little bit about yourself; how old are you sir?

Respondent: I am [redacted] years old.

Interviewer: Maybe before we do that, let me just mention where we are. Okay. Today is the 8th of November 2019. We are here in the Cardiology room, Mbarara hospital. Please tell a little bit about yourself; how old are you sir?

Respondent: I am [redacted] years old.

Interviewer: Okay, and then when did you qualify and where?

Respondent: [redacted]
[redacted]
[redacted]

Interviewer: [redacted]

Respondent: Yes.

Interviewer: How many years were those?

Respondent: Before I went for studies, [redacted].

Interviewer: [redacted]

Respondent: [redacted].

Interviewer: And how long have you been working here?

Respondent: For all that period.

Interviewer: all that period you have been working in Mbarara hospital!

Respondent: Yeah.

Interviewer: Okay. When you look at the demographics of the patients practice, what are the common illnesses you usually see by age group? You can say that between this, among the pediatrics . . .

Respondent: Okay, um, the commonest mostly in adult patients above 18 years, we commonly have the GI conditions, we have of course . . . we have the communicable conditions like the malaria, respiratory tract infections and then in the non-communicable we have Hypertension and Diabetes.

Interviewer: Okay, thank you so much, and then um, tell me about your training in RHD, have you received any specific training on RHD maybe during school.

Respondent: During school of course we study it as one of the conditions but after that I have not had any other additional training specifically.

Interviewer: For RHD!

Respondent: Yeah.

Interviewer: Have you had any CMEs about RHD?

Respondent: CMEs, not really.

Interviewer: Do you think they are important?

Respondent: Yes of course they are important because whatever training you undertake, you get the knowledge and this knowledge is usually applied in the management of patients

Interviewer: so um, have you seen um, in the recent past, have you seen any RHD patients here? Have you worked on any?

Respondent: I have not worked on any in the recent past although I encountered one. It was quite some time back.

Interviewer: When was that? Like how long was the period?

Respondent: It was around 2, 3 years.

Interviewer: 2, 3 years ago? But in the recent years?

Respondent: In the recent years I have not interacted with any.

Interviewer: Those ones that you saw three years ago, how do you describe them? Typically, who are these patients, and were they out patients or in patients? Were they young or old?

Respondent: This one was a middle aged person who had been on care for some time and, of course he presented with an exhibition of the symptoms but he was on care except that he was not regular on his medications and I think that's why he was getting exaptation of the cardiac symptoms.

Interviewer: okay, so you said by middle age, which age is that?

Respondent: He was around 35years.

Interviewer: And was he an outpatient or inpatient?

Respondent: He came in as an outpatient.

Interviewer: Okay, and um, I am interested in knowing what is your understanding of the causes of RHD?

Respondent: Okay the causes, those that I know of are . . .

Interviewer: Or what you were taught.

Respondent: Auto-immune condition which affects the joints and then, because the tissues of the joints are similar to those of the heart, then the heart ends up getting affected also.

Interviewer: Okay, thank you. And then um, are you aware of a link between sore throat and RHD? Are those two related; sore throat and rheumatic heart disease?

Respondent: Yes, because when someone gets a sore throat um, okay of course in most cases the cause is bacterial and being bacterial, the body creates a defense mechanism and those antibodies that are produced as a means of fighting off the infection also affect the heart muscle.

Interviewer: Thank you. And then what were you taught in school that can be done to prevent RHD?

Respondent: Of course when someone gets signs, he has to get um, to seek medical attention in terms of getting treatment quick treatment because when it stays for long, that's when he gets cardiac problems and complications.

Interviewer: okay, and then what were you taught as some treatment options for RHD?

Respondent: Umm, in terms of bacterial infections we give antibiotics which are Penicillins, then because of the inflammation, we can also give steroids and if there are signs of heart failure, then we can give also heart failure drugs.

Interviewer: okay, thank you. Then what is your understanding of the long term prognosis of RHD?

Respondent: um, prognosis, depending on how someone is a compliant to the drugs; if he doesn't adhere to the treatment usually the prognosis is not so good because they usually tend to go into failure and when they go into failure, then it makes there life not pleasurable.

Interviewer: So tell me about your encounters with the patients of RHD? You told me there is one you saw three years ago!

Respondent: Yes.

Interviewer: and um, that was that the last one you saw?

Respondent: Yes.

Interviewer: And you said he was around 35?

Respondent: Around 35 years.

Interviewer: around 35 years old. Okay, did he look like a person who was working? Was he in school, was he not working, typically how was he?

Respondent: okay, he was working but the nature of his work wouldn't be comprised by his condition except when he has exacerbations.

Interviewer: What kind of work was that, if you recall?

Respondent: yeah, he told me that he had undertaken a course in tailoring and he was working as a tailor.

Interviewer: okay. When you look at those patients, do they know that there's a link between a sore throat Acute Rheumatic Fever and RHD? Do you think they have a clue?

Respondent: No, they don't have a clue.

Interviewer: What sort of symptoms do they describe to you when they come? What do they present?

Respondent: when they are presenting, they usually would present with joint pains and subsequently they would develop features of heart failure where they have easy fatigability, they have edema, the swelling of the limbs. Those are the most clinical whatever, symptoms they present.

Interviewer: okay. When you look at follow up and adherence, how are they adhering? Do they come when you call them for follow up?

Respondent: Yeah, because there are few that I have attended to, the one that I attended to of course came because he had issues but initially he was given treatment which I cannot say he was adhering to because if he had adhered to, he wouldn't have come with the symptoms.

Interviewer: Why do you think they are not adhering?

Respondent: why they are not adhering, I think, and this my personal opinion; it is because when they take medication and they get some bit of relief, it makes them think that maybe they won't get the problem anymore and get relaxed in taking the medications.

Interviewer: And when you give them appointments to come back, why do you think some people don't come back?

Respondent: I think it's because um, they lack the knowledge of their disease condition, of course not knowing that they need to adhere to the medication. So they end up getting the complications.

Interviewer: So where is the gap in the . . . what can be done?

Respondent: I think what can be done is to educate them on their conditions, what they are supposed to do and what can be done to adhere to the medications.

Interviewer: Currently is the health system not catering for their education in your own opinion?

Respondent: For sure it's not catering enough for giving information regarding RHD.

Interviewer: Where could be the problem?

Respondent: The problem could be in um, of course it starts with the health workers because we are the ones to give information to the population.

Interviewer: but what could be stopping the health workers from doing that?

Respondent: Of course now this one is much factorial. One; the staffing levels within the hospitals. Then two; although we study these conditions in school, we also a need for a continuing medical education on those conditions so that the health workers themselves also have the information which Information they can to pass on to the population.

Interviewer: **okay.** You have talked about staffing; what is it about staffing?

Respondent: The staffing levels are low I may say, because like now when you consider, of course there are many cadres. When you go to the nurses, they will tell you they are not enough. When you consider the clinicians, the staffing is also not adequate in most cases.

Interviewer: Okay, thank you very much. We have talked about some of the things that are stopping them from coming and you said when they feel better, they can relax.

Respondent: Yes.

Interviewer: Which other reasons apart from ignoring the fact that when they get better they relax? What else do they say when you tell them to come back this month they don't come back.

Respondent: Of course also their social-economic status can limit them because if someone is coming from far, at times they will give excuses that I didn't come because I didn't have transport, such things.

Interviewer: So transport is the problem?

Respondent: Yeah.

Interviewer: Any other that you can think of?

Respondent: Yes, and even the cost of the medications because in most cases, some of the medications that can be prescribed for them might not be available in the hospital. It can also be a limitation.

Interviewer: So does that mean that probably there are some drugs that are not available in the hospital for these patients?

Respondent: yeah. I am not saying that they are not available, okay they are available but there is some duration of stock outs.

Interviewer: It is okay. Okay, good. And then um, I am going to ask you about the barriers you face as health workers later. But let's now concentrate on the local health system barriers. I want to see which pieces that am going to mention are working for you and why you think they are working for you? Let's first look at the administration here and the leadership in the district; is it working for you when you're caring for these patients? Are there issues or you feel it is working fine, you don't have problems with the administration when you are doing with the patients?

Respondent: No, when I am doing my work, I think the leadership is doing what is possible to see that we give good care to our patients. I don't have any problem on that.

Interviewer: How about the administration here in the hospital.

Respondent: I think it's the same; they are doing everything possible so that we give quality care.

Interviewer: Why do you feel that way?

Respondent: Yeah, because one; of course as the staffs, the staffs are mostly motivated when they get their payments on time. Then two; um, although I said that there may be a stock outs at some time, they do what is possible to make sure that the drugs are available and of course the health worker also gets motivated when you, like, prescribe treatment and the patient gets the prescribed treatment.

Interviewer: How about the funding in general, is it working for you?

Respondent: In general?

Interviewer: Yes, before I go to the funding of RHD, let's first look at funding for health care in general for all the diseases that you take care of; how do you find the funding? Any issues you have there?

Respondent: I don't have any issues.

Interviewer: You are happy with the funding that is given?

Respondent: At least.

Interviewer: okay um, Of course you have talked about the health worker numbers and you have said.

Respondent: Yes the numbers are low.

Interviewer: How about the qualifications, do you have enough people with different cadres and different qualifications around?

Respondent: Well that's what I meant that when you go to the side of the nurses, the staffing is not adequate although the ones who are there are qualified, but the numbers are not . . . I think they are fewer than expected even when you go to the clinicians.

Interviewer: okay. Now let's look at the waiting time for our patients, how is it here?

Respondent: The waiting time, I am not so sure about how much they should be waiting but to me, initially the waiting time was okay because we would receive patients, the patients are triaged and then after the triage, we attended to the patients. But recently, they brought in a system whereby we have to enter the patients into the computer; that one has sort of increased on the patients' waiting time because you know it's a slow process. It increases on the time because they have to be triaged, entered into the computer and then seeing them on the computer also is a problem because the system is not fully functional, so there are some things which have not been put in place to make it fully functional and it ends up increasing on the patients' waiting time.

Interviewer: okay, so on average how much time does a patient have to take?

Respondent: From the time the patient enters into the hospital to the time he sits um, roughly, what can I say? Anyway that one varies depending on whether the patient has been sent for investigations or not, but if the patient has not been sent for investigation, he can spend like three to four hours.

Interviewer: 3 to 4 hours. Then with investigations?

Respondent: With investigations, it can go up to, it can go to five to six hours.

Interviewer: Okay and If you look at the quality of care, if you look at it in the perspective of numbers of health workers, what do you have to comment about the quality of care you give to the patients?

Respondent: The quality of care versus the number of patients, I feel if the staffing is improved by providing more staffs, then I think the quality will improve more.

Interviewer: But how is it right now?

Respondent: um, what it is now is that because of the fewer patients it doesn't compromise the quality but maybe as you said it increases on the patients' waiting time and of course when the patients wait for long, they tend to get discouraged.

Interviewer: Let's look at the medication; um, before I move on I forgot something which is important; how do you look at the funding for RHD in particular for this hospital or the country entirely? How is it? Are you happy? Is it working for you?

Respondent: For RHD, I cannot say for the nation specifically because usually when they are procuring drugs and things they use, they do them generally. But generally, I think with the care, there has been some gaps there and just like I told you, most especially the drugs, there are some times when there are stock outs and the drugs are not there. So generally I think even with RHD, it's the same thing.

Interviewer: Ok, because my next question was s about the medication and we are interested in the heart failure drugs, how are the stocks, anti-coagulation drugs, the BPG drugs. How are they in the hospital? For insistence you had that patient you had at that time and probably you prescribed something, did the person get it?

Respondent: Well the person was lucky that time because by the time he came, the stocks were available and he got some medications. However, there are some instances when there are stock outs.

Interviewer: okay, and then when you look at the diagnostics like ECHO-Cardiograph, do you have it in place? Can it be done here?

Respondent: Yeah, it can be done here but the problem that we have is that the ECG and ECHO here are private, so we consider that for a person who has come from the village and doesn't have much may not afford to have those investigations done. It would be okay if they are made to be free so that whether someone has the money or not, they can access the services.

Interviewer: How much do they pay?

Respondent: They pay, I am not quite sure; is it around 10,000shs?

Interviewer: around 10,000shs!

Respondent: Yeah, around 10,000ushs I think

Interviewer: Let's look at the way records are handled here, the medical records, do you have a system? You told me that now you do the recording on the computer.

Respondent: Yeah

Interviewer: Is that across all departments?

Respondent: That's why I told you that it's not fully functioning because it's not on all departments. They have started it with outpatients where I work now, but all departments have not been connected to the system.

Interviewer: Okay, I understand that. But now if I wanted a record of someone who came maybe four years ago, if you want to look at that patient's records, is it easy to get that information?

Respondent: Yes it can still be got because when we see patients, we record them in the registers and those registers are kept. Even when the patient is admitted, on discharge they give the patients the discharge letter and then the file is kept for records.

Interviewer: okay. Do you have any registers for ARF and RHD patients here?

Respondent: I think they are not specific; we have general registers.

Interviewer: um, are they integrated between inpatient and outpatient? Is there a clean flow like in case you need access?

Respondent: Yeah when you need access, I think it can be got but except that now the registers, the ones for outpatients are specific for outpatients and then those for inpatients also have their own registers for admitted patients.

Interviewer: Do you have any guidelines and protocols for RHD Care in this hospital?

Respondent: no, I have not come across those guidelines.

Interviewer: you don't have them, and do you have a clear referral pathway for RHD patients here?

Respondent: Yeah, the procedure is that when we see those patients, usually when they are in a state where they need to be attended to in the cardiology clinic, then we refer them in the cardiology clinic. But if their symptoms are mild, we prescribe treatment and then they go.

Interviewer: okay, would you think that guidelines and protocols for RHD patients would be useful?

Respondent: Yes, I think they would be very much useful because they would guide us on how to manage these patients.

Interviewer: As we are about to wind up, so the pieces that are working for you are; administration is satisfying

Respondent: yeah

Interviewer: Funding is you are okay with you

Respondent: Yeah

Interviewer: and health information?

Respondent: Yes.

Interviewer: If I say something that is not right you tell me.

Respondent: Yes.

Interviewer: And what is not working for you at least is that most times there are stock outs and the health workers.

Respondent: Yes.

Interviewer: Okay, any other health system barrier that you feel that it needs to be addressed?

Respondent: I don't remember any.

Interviewer: okay, there's none! Now let's look at perceptions about patient outcomes; generally do you think patients get the care that they need?

Respondent: Yeah, of course now for the patient's expectations is to be attended to by a clinician and then two; to get the necessary investigations, and three; to get the medications. For the clinicians, I told you that there is that staffing gaps. And then on investigation, okay the major investigations that would be done here are all paid for investigations. And then on the medications, when someone is lucky and comes during the time when there are no stock outs, then they will get medication. However, when the stock is out, then it means that the medication will not be got also.

Interviewer: In case like for the RHD patient who needs surgery can they access it?

Respondent: They can't get it here?

Interviewer: So what do you do for those who need it?

Respondent: Those ones, usually at my level, we refer them to the cardiologist but what I know is that they are usually referred to Mulago.

Interviewer: they are referred! Okay. Do you have any patient safety and quality of care concerns, as you?

Respondent: concerns! I can't think of any?

Interviewer: Do you think you have had some preventable deaths occurring in the hospital? You just look surely and say "that patient shouldn't have died. We could have prevented that but it occurred"

Respondent: But because I don't work on the wards and I am in OPD, I usually see the patients who are relatively stable. I think that could be the reason.

Interviewer: So you have not seen any preventable deaths?

Respondent: No, I have not seen any preventable deaths.

Interviewer: Do you think our patients dying in communities without presenting themselves to hospitals for care?

Respondent: Yes.

Interviewer: Why?

Respondent: one; um, because maybe they may be lacking information regarding their conditions, and then two; social-economic status when they can't afford to pay for whatever has to be done in terms of care. As I told you, in terms of investigations and medications when they are out of stock.

Interviewer: okay, thank you very. So in your opinion, give me one or two most important things Ministry of Health should do to improve the outcome of our patients?

Respondent: one; to improve on the staffing levels within the health facilities and then two; um, to provide um, I have failed how to term it; to make sure that drugs are available all the time so that there are no stock outs. And then three; to plan so that maybe the investigation are all affordable or can be accessed by all patients because if they are payable and someone can't afford them, they will lose out. And then three; maybe also to improve the motivation of the staffs.

Interviewer: In what ways?

Respondent: Because the staffs, although the salaries come on time but it's a prayer that when the salaries are increased, they will be more motivated to do their work.

Interviewer: Any think else before we stop?

Respondent: I don't have anything to add on.

Interviewer: Thank you so very much for giving us this opportunity to talk to you and we appreciate your feedback we shall use it with the views of others to improve care for our RHD patients.

Respondent: You are welcome.

Interviewer: Now I will hand you over to [REDACTED].

Participant ID	HW 002 -Mbarara
Date	8 /Nov/2019

Interviewer: Okay we are seated here in the clinic room. This is the 8th November, 2019 and the participant ID is WH002. So thank you so sir for allowing to come and talk to us.

Respondent: You're welcome.

Interviewer: Just to remind you, there are no wrong or right answers. We are interested in what you have to say to us.

Respondent: Okay.

Interviewer: So we request you to be frank and share your opinions.

Respondent: Okay.

Interviewer: The data we are gathering is going to be kept confidential and we are not going to link your identity to any of the comments we make in the reports that we produce.

Respondent: Okay.

Interviewer: So could you please tell me a little bit about yourself; how old are you?

Respondent: I am [REDACTED].

Interviewer: Wow! What are your qualifications?

Respondent: So I am a medical doctor [REDACTED].

Interviewer: Okay, and where was your first training?

Respondent: I first trained [REDACTED].

Interviewer: Okay. Nice to meet you.

Respondent: It's nice to meet you too.

Interviewer: So you qualified in which year?

Respondent: I qualified in [REDACTED].

Interviewer: [REDACTED]

Respondent: [REDACTED]

Interviewer: Okay, so how long have you been working here at Mbarara regional referral hospital?

Respondent: [REDACTED].

Interviewer: Okay. Before [REDACTED], where were you working?

Respondent: I was working at [REDACTED]

Interviewer: Okay. So when you look at the time you have been here, when you look at the demographics of your patients, what are the common illnesses that you have been treating as an HO?

Respondent: The commonest illness still stands as pneumonia followed by diarrheal diseases; diarrheal illnesses.

Interviewer: Does that cut across all age groups?

Respondent: No it doesn't, those are more common in the under 5 years.

Interviewer: Okay. Then among the adults?

Respondent: Among the adults! I have not dealt much in the adults but on a few occasions I have dealt with adults. Most of them come with cardiac related diseases, cardiac diseases then issues to do with women health and orthopedic complications.

Interviewer: Okay, um, tell me a little bit about your training on RHD? Have you received any specific training during school?

Respondent: Yeah, my training majorly has been based on lectures and also involvement with my tutors and lecturers, plus the colleagues especially those who run the current Rheumatic Heart Disease clinic. Because, personally I got interest and I have the initiative within myself that we should help these children. I was first introduced to by when he had just come to introduce it and not because he is my OB, but he's someone I knew plus the team. The fact that I knew them, the three of them, I got the interest in working with them. I have learnt a lot from them; the ECHOS, V-scans they do. We share with them, I have discovered many cases that I have never seen and we've also involved the pediatric cardiologist at our unit and it's really resourceful.

Interviewer: Wow that's good to hear. So like you said, you discovered new cases, like how many have you discovered that you've not seen before?

Respondent: The most recent one, the one I have not seen before is the Atrium Trauma. I just had it in theory, but I am the one who had the child, I took the child for screening and with unclear cardiac manifestations and we identified the findings on ECHO. Then the other one was Epstein anomaly, which I also had it in theory but I was able to look at it on the V scan.

Interviewer: Okay. So you said you got interested in RHD when you met the people working on the RHD project.

Respondent: Yeah.

Interviewer: Did they give you any training specifically in RHD management?

Respondent: Yeah. They just came and gave us an idea on what they had come to do, what they were interested in and they briefed us on part of their inclusion criteria. That one also helped me. With the inclusion criteria, if I find children with such, I help to link these children to the project.

Interviewer: Okay. So during school, what did they tell you about . . . okay, before you heard about it from the RHD project, in school, did they give any training in RHD management?

Respondent: Yes, it happened both in a lecture and also ground rounds. Even in the first year of Post-graduate, we had an organized ground round by our cardiologist and we all participated.

Interviewer: Okay. And then how many patients with RHD do you see per day?

Respondent: I can't say this is the exact figure, but anyway being a regional referral hospital and also being attached to children's hospital, on average I see 1 to 2 per day.

Interviewer: Okay, and then . . .

Respondent: Some of them are referrals and then others may not know, but after linking them to the project or to Doctor the cardiologist, they are identified.

Interviewer: Okay. And then um, so most of them are out-patients? Were you are in the outpatient or you're also?

Respondent: Of course inpatient and outpatient.

Interviewer: So most of them that you see are in . . .

Respondent: Yeah, most of them are apparently referrals in. Because of the project, the announcements which were run, the different health workers that suspect the symptoms, they refer them and we receive the patients.

Interviewer: So you made some announcements?

Respondent: The project made some announcements to create awareness.

Interviewer: Using what?

Respondent: Using radio talk shows.

Interviewer: So they've had an impact!

Respondent: Yeah, they have had an impact because I have worked for 3 years in the region and working in a children's hospital has made me have a somehow big clientele, so I get calls and calls: "my child has this and this", "we heard that there are people who work on these children, where can we find them? Please can you help locate them?" like that.

Interviewer: Okay. So I am interested in what you have been taught about RHD; what is your understanding of the causes of RHD?

Respondent: So Rheumatic Heart Disease per say comes as a complication of Rheumatic Fever and the commonest cause is the molecular mimicry arising from the toxins released by the Group A-Beta hemolytic streptococcus. The most common origin is from a skin infection but a throat infection also has a contribution and it is seen that the Rheumatic Fever will develop in 2-3 weeks with the classical features

of the John's criteria. However, when not managed, it can progress into complications among which is cardiac involvement as Rheumatic Heart Disease.

Interviewer: Wow! Okay. My next question may not even be valid because it's asking if you are aware of the link between sore throat and RHD, but you mentioned it in your previous response. So what have you been taught can be done to prevent RHD?

Respondent: First of all, for any child who comes with sore throat or a skin infection, they must be managed well with following guidelines, that is, a minimum of 10 days of good antibiotics preferably following Culture and Sensitivity. But if culture and sensitivity is not done, at least Penicillin Paste Therapy is the best for a minimum of 10 days and these children receive a baseline ECHO, then an ECHO at 3 months and then a repeat ECHO at 6 months.

Interviewer: Okay.

Respondent: Yeah.

Interviewer: And then um, so what were you told are the treatment options for RHD?

Respondent: So the treatment options depend on the severity and the stage at which the child has presented. If the child comes in with a Carditis picture without features of decomposition, then you give them monthly Benzathine for a minimum of 10 years. But for those ones who come with severe cardiac manifestations, they are given for life or until they make 45 years of age. However, there are other managements, some of them come with a complication which could be effective endocarditis arising from Rheumatic Heart Disease and ideally, may need replacement of the valves and other forms of surgery to keep the child breathing.

Interviewer: Okay, thank you. And then what is your understanding on the long term prognosis of RHD?

Respondent: So once identified early the prognosis is good, but once identified late as most children come in, the prognosis is really poor and most children usually fall out of follow up. But once we keep them in the follow up cohort, then it helps us manage them appropriately.

Interviewer: Okay, why do they come late?

Respondent: Some of them are unaware; the parents are not aware and others meet health workers who don't have the knowledge to diagnose. Then others come and actually miss the treatment when they reached the facility; you write for them treatment but it's not available especially in government facilities, but some other parents actually are given treatment but they don't take time to follow up with the strict instructions.

Interviewer: Okay thank you. Now, can you please recall the last patient you saw who had RHD and summarize that visit for me? How was it?

Respondent: Yeah. The last patient was actually a referral-in here and they thought the child had anemia following malaria, but they were treating a child for anemia but with a negative blood smear. So the child had fevers and came in with severe Pallor and had features of heart failure, but on listening to the heart and looking at the body, the child had features which were fitting the child in the criteria for Rheumatic Heart Disease, so an ECHO was done and confirmed the findings.

Interviewer: Okay, so how old was that patient?

Respondent: The child was 8 years old.

Interviewer: Okay, so was he in school? Could you be knowing?

Respondent: Yeah, the child was school going but had been out of school for the last one month. He was coming from Isingiro.

Interviewer: Okay. When you look at our patients, the RHD patients, are they aware about the link between sore throat, Acute Rheumatic Fever and RHD?

Respondent: I think there's still that knowledge gap including actually health workers, and not only the parents and the children themselves but including health workers. Some of them take it for granted, but there are some who know and have the information. I have come to understand that following the ongoing study in the region at least there's there is an idea. A percentage of knowledge has improved.

Interviewer: It has improved!

Respondent: Yeah.

Interviewer: Okay. So what sort of symptoms do they describe to you when they come?

Respondent: When they come they describe easy fatigability; the child gets tired easily and then for the older children, those above 5 years, they can also report the heart beating a lot what I can medically interpret as palpitations. And, some of them come with a fever and others don't. Some of them remember that they had a recent throat or skin infection and others don't.

Interviewer: Thank you. And then, are they good about follow up and adherence? When you tell them "come back on this day", are they brought?

Respondent: Once parents are taught about the relevance, they surely come back. I understand there is a small percentage of those who are unable to afford the transport, those who are adamant and they don't really take it seriously that their child may end up with severe complications, but with the health talk given to them on every visit and the updates on the progress and the future plans for the child, most of them come back. Maybe what I should add to make it improve is having strict days; at least every facility especially those who see children regularly should have strict days and they know that "whenever I go on this day, children are seen in this area and this is the reason." Because, some of them come on any day and they may end up getting lost in the hospital and they end up as missed cases.

Interviewer: Okay, and then with adherence, are they adherent to the drugs?

Respondent: Yeah, some parents complain especially about the Benzathine being painful but there other remedies that are being done, giving it with Lignocaine 10%. However, an injection is an injection to the child and there are some parents who are adamant; once the child cries, they think the health worker is harming the child so they may not bring the child back. But counselling and telling them the relevance has helped to improve the adherence, plus other heart failure drugs.

Interviewer: Okay. So do you have some people who do some counseling here for them or is it . . . ?

Respondent: Ideally we usually do it ourselves.

Interviewer: The doctors!

Respondent: Yeah. There's no one employed that there are counselors in the clinic to do that; we do it ourselves.

Interviewer: You do it yourselves! Okay. And then, what sort of barriers do they commonly state? I

Know you have mentioned some of them but to get more...

Respondent: Specific?

Interviewer: Yeah. What barriers do they state in getting the care they need?

Respondent: First of all its transportation to come for the reviews then secondly, the accessibility to the medicines. The major reason for accessibility is finances; most of the cardiac drugs are ideally expensive so they cannot sustain the medicine. So some of them have the issues of failing to complete the treatment because they do not have the money.

Interviewer: So on a typical visit, how much would an RHD patient spend on drugs?

Respondent: So, Ideally here in a regional referral, we don't know because sometimes the drugs are available and sometimes drugs are available. So what we do is that we write for them and they go to the pharmacy because we ourselves have no right to . . . even if we are sure drugs got out of stock, we do not have the right to tell them that because it's the pharmacy people to do that. So we rarely know whether they have bought or not bought the drugs and at how much.

Interviewer: Okay. You told me this one, because it was asking me about barriers you perceive they face but you said that financially all that. So now let's go to local health system barriers, now we are looking at the health system where you are part of.

Respondent: Yeah.

Interviewer: We would like to know which pieces are working for you, from the ones I am going to mention and why. We also want to know the ones that are not working for you and why? Let's look at administration and leadership in the district; is it working for as you are doing your work here and taking care of patients?

Respondent: I should say the administration and the leadership right from the DHO's office, they are supportive and there are sometimes some loop holes here and there but at least they are doing their best. And the advocacy, because once you reach for them, they help us and they really try to advocate for these drugs to be available, actually especially this hospital given that the fact that the deputy director is a pediatrician and a consultant. So children really get the priority in this hospital.

Interviewer: Okay, when you look at the funding for the health care in general, is that working for you and why?

Respondent: The funding is not working.

Interviewer: Why?

Respondent: Because most of these drugs must be available at all times for us to have sustainability of the services provided.

Interviewer: Okay. And then um, for RHD in particular, how is the funding?

Respondent: There's no specific fund for RHD, like in the department I am attached to.

Interviewer: Okay.

Respondent: But the only maybe benefit we have, is the Pediatric Cardiologist who is trained and an employee, not visiting.

Interviewer: Talking about the health workers and the numbers that are here, when you look at the numbers and their qualifications, are they working for you?

Respondent: Yeah, I feel that given that in this hospital most health workers in the facility are actually residents who are learning and at the same time treating the patients. So I think the technical know-how would be adequate for basic needs of these children with rheumatic heart disease.

Interviewer: Okay, how about the numbers?

Respondent: The numbers are enough.

Interviewer: They are enough!

Respondent: Yes, they are enough.

Interviewer: Waiting time of the patients!

Respondent: Yeah. Waiting time is still a problem because the target is usually 45 patients for every patient, however, sometimes a patient comes, they are like 10 of them, they don't have a specific time of coming and being a clinic, by midday to 1pm we want to close it and do other department activities. So certain times we tend to extend it because patients have come in late and they are many and they only have two major days. Wherever a patients comes we have to attend to them but especially for the reviews, they are on Mondays and Tuesdays. So waiting time is still a problem.

Interviewer: On average how much would . . . per patient?

Respondent: On average I have realized it is 1 to 2 hours.

Interviewer: 1 to 2 hours of waiting. Quality of care; what do you have to say about it?

Respondent: quality of care, from a scale of 1 to 10, I would put it at 5.

Interviewer: At 5!

Respondent: Yeah.

Interviewer: Why?

Respondent: Why? One; we have a person who spearheads, one who is guiding the Pediatric cardiologist and then in addition to that, we have the residents who are pediatricians. We also have other stakeholders

like people from the research team. Often when the cardiologist has not been on ground for some time for maybe some administrative reasons, we've got these students. So we always have plan B.

Interviewer: So you said 5, so there's that other 5!

Respondent: Which is meant to make it 100%?

Interviewer: Yes.

Respondent: That one entails the drugs, accessibility, availability, the time they spend, the duration they take in the hospital, those who are unable to come back and are unable to fund their transport because they can't afford. So that takes the other 5.

Interviewer: So we've talked about medication. And um, let's look at diagnostics particularly ECHO-Cardiography.

Respondent: Yeah.

Interviewer: Tell me in this hospital.

Respondent: In this hospital it is done at 2 sites; one, at the Pediatrics' department and two, in the tent where there's a study going on. However, in the study they also work hand in hand with the Pediatric Cardiologist.

Interviewer: So is it for paying? Do they pay?

Respondent: No, it's free of charge.

Interviewer: Okay. That's good.

Respondent: Including all the tests.

Interviewer: Let's look at these medications, the heart failure drugs, anti-coagulation, BPG. How are the stocks?

Respondent: The stocks are on and off I should say and sometimes they are off and we don't know from the pharmacy because they don't communicate to us. Sometimes they are present and we don't know, We don't get feedback to write what we think is best for the patients because we always have a scope of drugs but you sometimes look at the patient and you say "perhaps if the drug is not available, for this specific drug, the patient can look around and buy."

Interviewer: so how can you improve that?

Respondent: So I think it all comes from the procurement system of the hospital and the Ministry at large; if they make it a priority for all cardiac diseases, actually most non-communicable diseases are being neglected.

Interviewer: How about the communication within this place so that if you are prescribing, you know which drug is available.

Respondent: Ideally I don't get any information from the pharmacy. On most occasions, I write and the patient goes.

Interviewer: Okay. Now let's look at the health information or the medical records system here, how is it? Is there any integration between inpatient and outpatient? Is there a clear flow of records?

Respondent: Yeah, we have books; the HMIS books, the red books, both for inpatient and outpatient and you can easily track the patient that you want.

Interviewer: So you find that okay?

Respondent: Yes, and for the admitted, we keep them in their record files.

Interviewer: Do you any registers for ARF or RHD patients here?

Respondent: In the cardiology clinic, we have a register in specific and it helps us follow up and stage the treatments that these patients.

Interviewer: Let's look at what has worked for you, factors that have made you do your work. You said the administration has made you do your work.

Respondent: Yes.

Interviewer: You said the health worker numbers.

Respondent: Yes. Then the resources to use; the ECHOs at least.

Interviewer: Okay. Yes you have that.

Respondent: Not enough but at least having one at the department and then the other one at the research project of Rheumatic Heart Disease gives us options.

Interviewer: Any other enabling factor that you can look at and say "yeah, this one has worked for me" and has enabled me do my work"? Probably one that I have not mentioned.

Respondent: Yeah. I think I should also say that the region where I am working is helpful because this is a region where health seeking behavior is improving, but there are certain regions you go to and you really need to take a lot of time to convince people about their health. But at least in this region people adapt easily to health seeking behavior.

Interviewer: What is unique? What are the factors behind this region?

Respondent: I think one of it is being situated in the town; most individuals are educated. Yes we still get those from distant places but the fact that they come, you can see that there is some bit of improvement.

Interviewer: Okay. We are on the last question. Do you think our patients are getting the care they need here?

Respondent: I think the patients are getting the care they need only that once drugs are made available, once we avail means of reviews of these patients, then we shall have moved a step.

Interviewer: Okay. Do you have any patient safety or quality of care concerns?

Respondent: Yeah, I should say so because often we prescribe these medications. Cardiac medications for example, Digoxin it's what patients can easily acquire, however, it has its toxicities and often we don't, always actually, we do not go to communities to assess these children. Some of those who die, we don't

know whether it's the drugs that we have given them. Some of them who maybe get complications, we may not get feedback.

Interviewer: Okay. Wow! So what would be your recommendation?

Respondent: I think my recommendation would be, the way for example, the government put up village health teams, if there is a system that can be created whereby we have a proper follow up plan, individuals who are facilitated in one way or the other because Ministry has many ways of facilitating individuals, it could be transportation of health workers or individuals to give them health visits. So if they are facilitated to always go and follow up these patients and do extended teachings to these patients even when they are at home.

Interviewer: When they are at home!

Respondent: Yeah.

Interviewer: Okay. So have you witnessed any preventable death occurring in this hospital?

Respondent: Yeah, I have.

Interviewer: What was the scenario here?

Respondent: The scenario was; a child was 9 years old came in and was in end stage. So to me that was preventable and this is a child who was referred in from the peripheral unit. So if the child was diagnosed or identified early, then that death would be preventable.

Interviewer: It would have been preventable! So do you think patients are dying in the community without presenting to the hospital for care?

Respondent: Absolutely yes.

Interviewer: Why?

Respondent: Because of the knowledge gap; some of them don't know what they are dealing with especially health workers, and others don't know who to reach out to in case they get a complication.

Interviewer: So in your opinion, give me one or two most important things Ministry Of Health could do to improve the outcomes of our patients?

Respondent: Ministry of Health.

Interviewer: Yes.

Respondent: One; reinforcing the health workers with one; knowledge and then the numbers. If we have a good coverage of these clinics, then it would be very important. Then two, the equipment; the ECGs and ECHO, because now like a regional referral, we have one major ECHO machine if the study decides to stop! So that machine needs servicing meaning we've got situations where it's down and children are not being ECHOED to know what's going on with their hearts. So Ministry of Health should look for a backup. Then also follow up plans for these patients; I wish they put up a platform of following up these patients.

Interviewer: Okay, any questions before we finish?

Respondent: Maybe the question I would pose; how long is this study going to go on and how will the public receive feedback? Will it be through radio talk shows? Because for me, I have seen it help and improve to increase the cases that actually come to the hospital.

Interviewer: Okay. For the qualitative, it is not going to be long because so far we started the qualitative in November. We started with Lira, and we have been in Wakiso and we are here in Mbarara. So the qualitative will end with Mbarara probably by the end of December but for the quantitative which these ladies are working on, that one is still going until June. And then for the dissemination, we intend to have a publications and then we shall a dissemination seminar at the end of the day to share our findings and we shall call some stake holders to join.

Respondent: It would be very helpful.

Interviewer: Thank you very much for your time.

Respondent: You are welcome.

Interviewer: We appreciate your views and we shall use them to see how we can improve our patient care.

Participant ID	HW 003 -Mbarara
Date	8 /Nov/2019

Interviewer: We are in the cardiology room at Mbarara Regional Referral hospital. Today is the 8th of November 2019 and this is Health worker 003. Okay, nice to meet you madam.

Respondent: You're welcome.

Interviewer: Thank you for allowing to speak to us. Just to remind you, there are no wrong or right answers and this study is meant to determine how to provide better care for RHD. Please be frank and share your opinions and the data we gather is confidential; we will not link your identity in any of the comments or reports we produce. Can we go ahead?

Respondent: We can go ahead.

Interviewer: So please tell me a little but about yourself; how old are you?

Respondent: I am [REDACTED] years old.

Interviewer: What are your qualifications?

Respondent: I am a nurse.

Interviewer: Okay, where did you train from?

Respondent: I have gone to, okay like several trainings. I did my enrollment.

Interviewer: From where?

Respondent: [REDACTED].

Interviewer: [REDACTED]. Where?

Respondent: [REDACTED]

Interviewer: And then how long ago did you qualify [REDACTED]?

Respondent: Um, [REDACTED].

Interviewer: When did you start the degree?

Respondent: I started in [REDACTED].

Interviewer: [REDACTED]?

Respondent: Yes, [REDACTED].

Interviewer: And then how long have you been working here at the hospital?

Respondent: [REDACTED] years.

Interviewer: [REDACTED] years! When you look at the patients you see here and their demographics, what are the common illnesses? Who are your patients here generally?

Respondent: Right now I have gone to various wards, but right now my age group is between 15 and no limit, upper limit.

Interviewer: Okay, women or men?

Respondent: Both.

Interviewer: Old? You said most of them are?

Respondent: Above 15 years.

Interviewer: Then um, and which are the common illnesses you treat?

Respondent: Basically medical conditions. All medical conditions; stroke, malaria, cardiac diseases, kidney diseases, liver diseases, because I am in the medicine ward.

Interviewer: So tell me about your training in RHD; have you received any specific training in school about RHD?

Respondent: Of course like a course unit on that.

Interviewer: You had a course unit?

Respondent: Yeah, but not any special one but as a routine Rheumatic Heart Disease.

Interviewer: After graduation have you received any training on RHD?

Respondent: No.

Interviewer: You have not! How about CMEs, have you attended any about RHD?

Respondent: We attended one.

Interviewer: One. Where was that?

Respondent: It was within the hospital.

Interviewer: Here!

Respondent: Yeah.

Interviewer: Who organized that one?

Respondent: Eh, can I recall? But I remember a certain staff gave it.

Interviewer: they did! So in a day how many RHD patients do you see or in a week or month?

Respondent: Maybe let's talk of maybe a month.

Interviewer: Okay.

Respondent: Can a month really work anyway! Maybe I can say like in three months, I haven't seen any. There's one I last saw some 4-5 months ago.

Interviewer: Okay. So in a year you see like how many?

Respondent: Maybe 4, but it depends.

Interviewer: Okay. So the ones you usually see, are they outpatients or inpatients?

Respondent: Inpatients because I am at inpatient.

Interviewer: Now I am interested in what you have been taught. What is your understanding of the causes of RHD? What causes it?

Respondent: Okay, what I can recall, I was told that if streptococcal sore throat is poorly treated, it can progress to rheumatic. So we are actually encourage to treat and advise; in case any child gets sore throat, you have to get proper treatment for it.

Interviewer: So um, but you have answered that. I was going to ask about the link between sore throat and RHD? You know about it?

Respondent: Yes.

Interviewer: Okay. So were you told can be done? What were you taught can be done to prevent RHD?

Respondent: Of course we need to sensitize the community so that they don't take it lightly; any sore throat can lead to something bigger than what we expect. So we need to sensitize them so that they consult the people concerned in time to get proper treatment to prevent these diseases.

Interviewer: Okay. So what were taught are the treatment options for RHD?

Respondent: Yeah usually the treatment of choice is to give Penicillins to clear the streptococcus and then we need to look at pain management in these people, and to basically prevent complications which can lead to damage of the heart valves and all that.

Interviewer: So what is your understanding about the long term prognosis of RHD?

Respondent: [sighs] now in which context, because I know that this patient will be on drugs for long, will have to be coming back for reviews and you know at a certain point things can worsen and even he needs surgery if the valves are destroyed, then this patient can go out to be operated.

Interviewer: So tell me about your encounters with patients with RHD. You said the last the last one you saw was 5 months ago!

Respondent: It was like 5months ago.

Interviewer: So briefly summarize that visit, who was this patient?

Respondent: This was a 14 year old who has been repeatedly being admitted and was confirmed with Rheumatic Heart Disease. But what I understand is that we have been treating this boy and he had challenges; as you know we might not be having drugs, so that becomes a problem, but he would come in pain. We tried to manage then after some time they are discharged and within a few months he's back, so he was continuously being admitted, but now I have lost contact with that one somehow for sure.

Interviewer: Okay, why? He is no longer . . . ?

Respondent: You know follow up of these people is not very easy, so you will see them when they come to the wards.

Interviewer: What makes it hard to follow up these patients?

Respondent: Of course you know, a lot of challenges. For example these patients could find us on wards , when you discharge you give them appointments to come back and if they don't come back, you might not get all those funds to go to the village and fish them and bring them to the hospital, unless if they come back to the hospital.

Interviewer: Why don't some people come back?

Respondent: Why people don't come back!

Interviewer: Yes.

Respondent: One, it could be funds. Two, maybe . . .

Interviewer: Funds for what?

Respondent: For transporting and drugs. When they see that this disease is not going away however much you try to explain to them that it will be a long term treatment. Others maybe lose trust in us; we are treating something that doesn't go away and maybe they opt for other medicine, maybe the local medicines.

Interviewer: Okay, and most of the patients you have seen with RHD, are they working or not, are they school or not?

Respondent: I haven't seen anybody above 20 years.

Interviewer: Okay.

Respondent: It's always below.

Interviewer: Are they in school or not?

Respondent: They are on and off of school and they end up dropping out of school.

Interviewer: Why do they drop out?

Respondent: Because of the ill health.

Interviewer: Okay. Do you think these patients are aware of the link between sore throat, ARF and RHD?

Respondent: There's limited knowledge in that.

Interviewer: Why is it like that?

Respondent: Because even when somebody comes in with that, he will come when it has worsened. But getting the knowledge that "oh, I have got sore throat so I should attach it to something", I don't think they have that knowledge.

Interviewer: Okay. What sort of symptoms do they describe when they come?

Respondent: Usually, they have a fever, joint pains, they will complain of chest pain and breathing will not be okay. But mostly, it is pain.

Interviewer: Pain! Okay, so generally, are they adherent to drugs? How is their adherence?

Respondent: I can't generalize that because usually, no. The ones I have seen are of a young age, and if they drugs, they can take them but sometimes they bring in complaints, "my drugs were out of stock and I didn't have money to buy" So adherence becomes a problem, but some of them do.

Interviewer: They do!

Respondent: But you will find that the ones I have seen really are unable to cope up with up to date treatment.

Interviewer: Because of?

Respondent: Funds of course.

Interviewer: How about those you tell to come back, "come back next month for your injection"

Respondent: They can adhere for some time but then after a long time they are lost to follow up.

Interviewer: Why?

Respondent: They will give you those reasons like "I couldn't get transport to come to the hospital" not until then other bad symptoms come and then that's when they will wake up and come back.

Interviewer: So when things worsen, that's when they come back!

Respondent: Yes.

Interviewer: Okay, so apart from transport, then they only come when things get worse, any other barrier you see they face or they tell you that they face in getting the care they need?

Respondent: They are demoralized because they are treating something that is not going away.

Interviewer: Anything else?

Respondent: No.

Interviewer: Okay. Let's look at the local health system barriers. We want to see which pieces work for you among the ones I am going to mention and why you think they are working for you.

Respondent: Okay.

Interviewer: Let's look at the leadership and administration in your district.

Respondent: Okay.

Interviewer: Is it working for you?

Respondent: If you talk of administration, for example given the setting I am in, I will just look at the drugs that are brought to me, but I have not seen people specifically coming looking for that. We treat them as we treat other general patients, so I don't know how to reach that.

Interviewer: So with administration, in case you don't have drugs, in case you need maybe the funds, things you report to administration, when you report them, are they worked on? Do you get help when you need it?

Respondent: Of course there's a system that we have to follow. If the system has not brought those things in, they can get some emergencies but we still stick on the system.

Interviewer: So are you happy with the administration?

Respondent: Yeah, because it does what it can, yes.

Interviewer: How about leadership in the district now?

Respondent: At the district!

Interviewer: Yes.

Respondent: Have I really interacted with the district?

Interviewer: No?

Respondent: No.

Interviewer: Okay when you look at the funding of health care in general, is it working for you?

Respondent: In general?

Interviewer: Yes.

Respondent: As in Uganda?

Interviewer: Yes.

Respondent: No, it is not.

Interviewer: It is not!

Respondent: It is not because I would love to work in an environment where everything is at hand. A patient comes in, needs a drug and it's at hand not that business of "You go and buy this drug" or "we can't help because we don't have drugs." you know! Somewhere, it is lacking.

Interviewer: How about for RHD patients now, how is it?

Respondent: As I told you, I don't specifically treat only that group; we generalize everything.

Interviewer: Okay.

Respondent: Yes.

Interviewer: Let's look at the health workers, how are your numbers here? Is that area working for you?

Respondent: Woo, now what can I tell you about the numbers?

Interviewer: Are they okay?

Respondent: No, not even, what can I term it? Because, like, the nurse patient-ratio for example in my department, you may find that it is one nurse to take care for 50 patients! Now what are you going to do? So numbers are not . . .

Interviewer: How about the qualifications people have?

Respondent: Some of them are not regarded because you may be a diploma holder but you are working as a certificate holder; you are paid salary of a certificate holder. A degree holder is being paid as certificate holder! So that one also contributes to the demoralization and all that

Interviewer: What can be done? How can that be . . . ?

Respondent: Yeah, we just need the government to streamline things but you know it's a process which we appreciate, maybe one time we shall be there but at the moment, it is lacking.

Interviewer: Okay. When look at the waiting time for the patients, how is it?

Respondent: Compared to the numbers of human resource, the numbers would explain the waiting time. Because it is a small number, so how do you expect a patient to be get served so fast of course with triage and look at those who are very urgent, very emergency, but also the other ones came for the service. So the numbers will explain that.

Interviewer: How about the quality of care you provide?

Respondent: challenging, because you know what to do but because you are poetizing, you can't meet all. For example, if I have 4 patients who really need blood, 3 patients need oxygen but then there is another one who needs Ceftriaxone, so what do I do? I will priotize so you find the other is one missing out because of the work overload.

Interviewer: Work overload! Okay, so if you look at the medication, what do you have to say about medications like anticoagulation drugs, heart failure drugs? How are the stocks here, BPG?

Respondent: These days it has improved, it has really improved but the numbers consume it before, but it has greatly improved. The cardiac drugs have improved.

Interviewer: What has led to that improvement in your own . . . ?

Respondent: [sighs] do I know? I really don't know. But maybe, the statistics maybe, because these days we have so many heart problem patients. Maybe it can explain that but there's great improvement because even those expensive drugs that we were not used to in the hospital, now we have them though the patients are too many so they are consumed in a short time.

Interviewer: How about the diagnostics; the ECHO-Cardiography?

Respondent: Those ones are in place, at least the service is there but patients pay a small fee for maintenance.

Interviewer: They pay like how much?

Respondent: I am not very sure, but maybe 30,000shs for ECG and maybe 80,000shs for ECHO. I am not very sure about that but what I know is that they pay some small money for maintaining the machine

which has worked, because the other time it would break every month with no repairs, but I think that one is better; our patients can easily access those services.

Interviewer: And those who can't pay, what do you with them?

Respondent: Usually the in-charge of a certain ward or head of department liaises with the administration and we revise that.

Interviewer: When you look at your health information and medical records system, how is it? What would you say about it?

Respondent: I think we are losing out somewhere. It is not up to date because we would wish it is computerized. Because when a patient comes from the starting end, by the time you reach my end, I can easily know you but that is lacking. Even that stationary itself is on and off, so it is not easy.

Interviewer: Is there some bit of integration between facilities, inpatient and outpatients? Are things streamlined like you are inpatient and the patient has passed outpatient, is it easy to access these records?

Respondent: Usually what they do, when a patient comes to outpatient, he is assessed and if they think this patient should be inpatient, so they have to write a note, goes to accidents and emergencies and then that's where the patient starts then later taken to other wards.

Interviewer: What if that patients comes after 5 years and you need to look at that patient's history, is it easy to look at that patients records? How easy is it?

Respondent: What we do, what is on ground is that when a patient is discharged, he is given a discharge form with his/her own ID number. In case that patients come back with that number, it's easy to retrieve the file. But if he can't come back with the file but can remember maybe when he was here, records may be available, but if you can't remember anything, then it's a bit difficult.

Interviewer: Do you have any registers for ARF or RHD patients here?

Respondent: Not specific, it is general where we also record other patients.

Interviewer: How about guidelines and protocols for RHD care, do you have them here?

Respondent: It is general still; it is not specific.

Interviewer: Why is the situation like that in your own view?

Respondent: Unless when someone comes up with that interest, but I would look at the protocols for malaria, diabetes and it would be too much, so that's why we generalize things. But there are some diseases where someone picks interest and then he comes up something like that.

Interviewer: Okay thank you. How about referral pathways are they clear to you? Do you know where to refer RHD patients? Do you know the steps you take to do the referral?

Respondent: Like a patient has been inpatient or outpatient?

Interviewer: Maybe you can no longer manage that patient here and you have to refer them elsewhere.

Respondent: Of course if we fail here at our referral, then our next step will be the National Referral in Mulago. That would be our next step.

Interviewer: So we have mentioned very many health system barriers and certain things you have said they are working for you and others you didn't feel like they are not working for you. So you said administration was fine.

Respondent: Yeah.

Interviewer: If I say anything you don't agree to you can . . .

Respondent: [laughs]

Interviewer: Funding wasn't fine, it wasn't working for you.

Respondent: No.

Interviewer: Health worker numbers didn't work for you.

Respondent: Yes.

Interviewer: Medications?

Respondent: On and off but improved.

Interviewer: Health information, medical records system, that one you said it works for you?

Respondent: No.

Interviewer: You said it's lacking because you wanted to start using computerized.

Respondent: Yes.

Interviewer: Then for the guidelines and protocols.

Respondent: Not in place specifically for RHD.

Interviewer: Do you ever get CMEs? You said you attended one CME!

Respondent: Yes.

Interviewer: Do you think you need more?

Respondent: I think. Those are very helpful, you know after school you take so long seeing a patient that you even forget how to manage of such patients.

Interviewer: If they were to offer you training in RHD area, where would you want the training to be? In which specific areas of RHD?

Respondent: Of course in . . .

Interviewer: If they give you an offer to train you about RHD, where would you want it be?

Respondent: Like a small part of RHD, of course I would want the nursing part of it and the management.

Interviewer: Okay. And then for the last set of questions; let's look at your perception for patient outcomes. Do you think our patients are getting the care they need here?

Respondent: 50%.

Interviewer: Why?

Respondent: Because if I write you drugs and they can't provide! Yes you have got the right prescription but have you got the drugs?

Interviewer: Apart from drugs being a problem?

Respondent: I think the personnel to handle that are available; we the physicians and all that but the big part of it is the provision of drugs to those patients.

Interviewer: Okay. In case a patient needs surgery, can they access surgery? Maybe if an RHD patient is at that stage where they need surgery, would they get it here?

Respondent: Not in Mbarara here. Not in Mbarara; that one will need to be referred.

Interviewer: Okay. Do you have any patients' safety and quality of care concerns?

Respondent: As in my unit or?

Interviewer: Your stay here, what you see and observe, do you have any concerns about patients' safety and the quality of care that you provide?

Respondent: Yeah. You know in this place, we have so many patients as I have told you and human resource is limited. So you would love to do a lot for that patients including explaining in details about the disease and how to manage, but you know you can't do that because of man power, the time; you have a lot to handle in one setting.

Interviewer: Okay.

Respondent: So they miss out that.

Interviewer: Okay, have you seen any preventable deaths here in this hospital? Deaths that could have been prevented?

Respondent: And then you continue to die?

Interviewer: No, have you seen any person dying and you say "surely, this person shouldn't have died" maybe probably because of the care?

Respondent: Yeah, those are there.

Interviewer: Like which scenario can you give?

Respondent: Okay at times when we don't blood, patients really die.

Interviewer: You have some instances where there's blood!

Respondent: Yes. Patients will really die. Some patient's maybe they can ask for some expensive drugs that the government can't give us, those ones die. There are sometimes when we don't have oxygen, so those ones would have been prevented but patients are likely to die because of that.

Interviewer: Wow. So do you think our patients are dying in the communities without presenting to the hospital?

Respondent: Do you mean specifically for RHDs or generally?

Interviewer: Generally.

Respondent: So much. Without presenting to any hospital here or any health center?

Interviewer: Any hospital or health center. Anywhere.

Respondent: Yeah they do because we still have that perception that we can get native drugs and all that and then they end up not working out. So I think some of them die because of that.

Interviewer: In your opinion, give me 1 or 2 most important things Ministry Of Health should/could do to improve patient outcome?

Respondent: Where now? In the community or here in hospital?

Interviewer: In the hospital, anywhere they are. But let's start with the hospital.

Respondent: I believe that if we improve human resource, you bring the number of nurses to patients at least to 10, because it would have been 4, I think something would be better. And, stocking drugs; essential drugs and we don't those out-of-stocks I think it will be okay. Then in the community, the community lacks a lot; we need to sensitize them. As much as health centers are there, but still they don't man power to handle. So we need just need to go deep down and sensitize them and then we also facilitate those lower centers to handle those cases.

Interviewer: Okay. Anything else before we finish?

Respondent: Not really.

Interviewer: Thank you so much for your time.

Respondent: you are welcome.

Interviewer: We appreciate your views and they will help us come up with strategies to help RHD patients to get better care.

Respondent: How I wish!

Interviewer: Thank you very much

Respondent: Okay, you are welcome.

Participant ID	HW 004 -Mbarara
Date	8 /Nov/2019

Interviewer: We are seated here in the cardiology room at Mbarara Hospital, Regional Referral Hospital. Today is the 8th of November 2019 and I am with health worker 004. Okay, Madam you are most welcome, thank you for allowing to speak to me today. Just to remind you, we are finding ways of providing better care for RHD and there are no right or wrong answers. Whatever you say is what we want to know.

Respondent: Okay.

Interviewer: so be frank and share your opinions. The data we are gathering is going to be kept confidential; we are not going to put any identifiers on the things that we shall produce in our reports. Can we go ahead?

Respondent: Yes please.

Interviewer: Please tell me a little bit about yourself; how old are you?

Respondent: I am [REDACTED] years.

Interviewer: and um, what are your qualifications?

Respondent: I am [REDACTED].

Interviewer: Where did you train from?

Respondent: I trained [REDACTED].

Interviewer: Okay, how long ago did you qualify?

Respondent: Um, [REDACTED].

Interviewer: How long have you been working at Mbarara Regional Referral Hospital?

Respondent: About [REDACTED] years.

Interviewer: about [REDACTED] years! Okay, in your [REDACTED] years, what are the demographics of the patients you have seen; age, sex, are they married, not married? Generally.

Respondent: In relation to RHD?

Interviewer: Before we go there, generally the people you have seen?

Respondent: All sorts of age, gender, because this is a regional referral hospital; all health centers and units will refer here.

Interviewer: So what are the common illnesses you have seen by age group?

Respondent: Malaria, we have had HIV related conditions, meaning streptococcal meningitis, TB, HIV wasting syndrome.

Interviewer: Is that among the old or is it among the young?

Respondent: I have worked in medical adults and not so much in pediatrics, and I have also worked in surgery.

Interviewer: okay, thank you. So tell me a little bit about your training on RHD; have you received any specific training in school about RHD?

Respondent: Um, no, but just a simple presentation sometimes in CME.

Interviewer: That's all you received in school?

Respondent: In school I think we studied about Rheumatic Heart Disease, I think we did. It's long ago [laughs].

Interviewer: And then, after graduating, you said you had CMEs

Respondent: yeah

Interviewer: was that after graduation?

Respondent: In practice.

Interviewer: In practice!

Respondent: it has been during practice.

Interviewer: So who gave you the training?

Respondent: I think it was a CME.

Interviewer: Who gave you that?

Respondent: I think it was Doctor; she is a physician in internal medicine.

Interviewer: she gave you one talk. Was it recent?

Respondent: Probably early this year.

Interviewer: early this year! Did you benefit from that?

Respondent: Yes I did, it was important to know how bad sore throats are.

Interviewer: okay, and then um, so was it done here?

Respondent: Yes it was done here.

Interviewer: so how many patients with RHD do you see? How often do you see RHD patients before I even start?

Respondent: Currently I am deployed in surgical ward but before surgical ward, for some three years I worked on internal medicine. Clear diagnosis that I can recall are two.

Interviewer: What year was that?

Respondent: 2013 to 2016.

Interviewer: 2016! And those cases you remember, were they children or adults? How do you remember them?

Respondent: Huh, I think they were not children; one was 16 years and probably that's not a child. One was 19, a female; 19 years old.

Interviewer: Were they inpatients or?

Respondent: Yes, they were admitted that the time.

Interviewer: okay. So please tell me a little bit about um, what you were taught about RHD, what is your understanding of the causes of RHD? What causes it?

Respondent: What causes it is a sore throat that is probably not adequately treated.

Interviewer: um

Respondent: And streptococcus at large, infections.

Interviewer: Okay, are you aware of a link between a sore throat and RHD?

Respondent: Yes, after that CME now I know better.

Interviewer: But before?

Respondent: Before, probably I had forgotten the knowledge at school.

Interviewer: okay, so after getting that knowledge, when you look back, do you think there are some cases you probably just missed because you didn't have the knowledge?

Respondent: Yes, I think so. But in our set up, diagnosis is made up by the physician and as a nurse, it's the nursing care and treatment and probably other things.

Interviewer: okay, so um, what were you taught can be done to prevent RHD?

Respondent: Prevention is treatment of sore throats adequately, um for example people have a tendency where one is given antibiotics and they take them for three days yet the recommended dose is five days, and the moment you feel good, you think it is okay. So the adequate treatment is not adhered to.

Interviewer: So what were you taught are the treatment options for RHD? Which are the options we have?

Respondent: Penicillin. I don't know of recent, are we are still using X-PEN? But I know of Benzathine. That time when I nursed that young boy it was Benzathine. Why I remember Benzathine, I gave it to the boy and he collapsed. I remember it vividly.

Interviewer: He collapsed?

Respondent: Yes.

Interviewer: How did you handle that?

Respondent: We had to put him on IV fluids because when he collapsed, he actually started sweating. Well, we took the IV fluids, we took the vitals and he later came up and he was like “what has happened?” Oh! It was too painful; he was wasted and to get the muscle where to give the IM, I think that was probably . . . it was monthly. He would come but when he got discharged after getting a little better, before actually the next dose, he’s back and in a worse situation. That’s the young boy I remember clearly.

Interviewer: sorry. So what is your understanding of the long term prognosis of RHD?

Respondent: um, actually the two that I have talked about have long died. So the prognosis is very bad; they are sick for a very long time and I think that young boy we nursed for about three years.

Interviewer: So it’s poor!

Respondent: Yes, it is poor.

Interviewer: So um, you have told me about that young boy and that was how many years ago?

Respondent: Probably between 2013 and 2016.

Interviewer: so was he in school, the boy?

Respondent: Yes it was a boy.

Interviewer: No I mean was he in school?

Respondent: um, I don't remember that bit.

Interviewer: you don’t remember that bit! Do those patients know the link between a sore throat, ARF and RHD?

Respondent: I don't think so. They may not know, because I think even the health workers will treat the sore throat but will not treat the . . . Probably when we know, we treat the sore throat then that is it; we end there. Because I think um, sore throat and Rheumatic Heart fever, one progresses after the other and if it's not adequately managed, then it goes to the heart disease.

Interviewer: okay, so um, what kind of symptoms do they usually describe to you they come; the RHD patients? What do they say they are suffering from?

Respondent: They talk of a fever that is constantly there. Um, they talk of joint pains. I think he also had chest pains.

Interviewer: okay. And then, are they good at follow up and adherence, our patients.

Respondent: Like I have told my experiences about those things. That time we had a clinic, I think it was in the medical clinic, the mother would try to bring the young boy in the clinic for follow up.

Interviewer: She did?

Respondent: And the regular injection, the monthly Benzathine.

Interviewer: okay, so that mother was bringing.

Respondent: Yes.

Interviewer: what do you think prompted her to always come? Because I know even if it's not among the RHD patients, I know there are some people whom you give appointments and they don't come back, but with this mother you said came back. What do you think made her come back?

Respondent: I think she came to understand the condition the child had and probably she would see the improvement somehow though minimal. Probably she was like "if I don't go, what will happen if I don't follow the reviews?"

Interviewer: For those who don't come back, what are the barriers; what is stopping them from coming back? What do they tell you that stops them from coming back? Okay let's start with what they will tell you.

Respondent: Generally, some of them will tell you "I come from very far. Since you have managed me and I feel better, I can be followed up where I am." Majority are quite poor; even if they would wish to come, things like transport um, is quite hard. But some of them still, even if you nurse them, now this is general; they think they can be healed through payers while others still think they can be healed through witchcraft.

Interviewer: okay. And then um, let's look at the local health system barriers. Which of these pieces that I am going to mention are not working for you and what are the reasons? And those which are working for you, you also give me the reasons. Let's look at the administration and leadership at the district and even here; is it working for you when you are taking care of your patients? Are you comfortable with the administration and is it facilitating you to do your work?

Respondent: That's probably a hard one. Maybe I would look at it in terms of utilities but our utilities come through NMS (National Medical Stores), and of course orders are generated here and then to NMS. Of course they are not very prompt; some utilities can miss and then nursing in all patients is a little hard.

Interviewer: okay, leadership at the district, is it helping do your work well?

Respondent: Well, I don't know the link between the District and the Regional Referral Hospital; I don't know who is bigger than who? [Laughs] I am not very sure.

Interviewer: okay. Do you ever get supervision from the District leaders?

Respondent: No.

Interviewer: okay. Let's look at the funding for health care, how is it? Is it working for you?

Respondent: funding, I think not. I know little about the budget, the Ministry of Health budget, I see there is 7.4% and then the budget cuts for regional referral hospitals is quite small.

Interviewer: and then um, how about for RHD, is there any vote for RHD?

Respondent: I wouldn't know that; I think it's all being managed under internal medicine and not separated.

Interviewer: okay. And then um, let's look at the health workers, how are the numbers and qualifications? Are you happy? Is it working for you?

Respondent: Ho! Human resource is quite wanting. I will give you an example in currently the surgical ward; the average daily census is 90 patients and the duty schedule, there are 7 qualified nurses dividing themselves into those shifts; evening, night and day and yet one must be on leave, one must take their offs. The human resource is not good at all.

Interviewer: How about the qualifications you have around?

Respondent: the qualifications, yes they are enrolled, there are nursing officers.

Interviewer: Any specialist who can handle RHD?

Respondent: um, I am not certain if anyone has been trained in specifically that.

Interviewer: How about the waiting time for our patients, how is it?

Respondent: When they come in the outpatient clinic or generally?

Interviewer: I mean generally.

Respondent: You know in outpatients, I have not been part of the outpatient clinic.

Interviewer: And then the quality of care that you provide, how is it when you look at it?

Respondent: um, the quality of care, it's probably, it's greatly hindered by the limited human resource and the limited utilities, and the infrastructure is small. Probably there are young children, young adults and adults would require a unit of their own but the space here is too small. It's too congested.

Interviewer: Let's look at the medication; are the patients with RHD, some may want heart failure drugs some may want anti coagulation drugs, BPG, how are the stocks if you look at them?

Respondent: as far as I can recall, we have never run out of Benzathine and the anti-diuretics. Um, blood supply, probably not, but sundries and other utilities that go along.

Interviewer: Which are those utilities do you usually lack?

Respondent: Syringes and gloves.

Interviewer: wow! How about the diagnostics especially the ECHO Cardiography?

Respondent: Echo cardiography is available but at a cost. I don't know how often it should be done but for those who are supposed to get it, it will take time for them someone to get the funds to get it done.

Interviewer: wow! So if it's recommended for a patient who can't afford, what is done?

Respondent: um, patients who can't afford, last time we used to have what we call a Poor Patients' Fund; we would find out how much it's costing and then we would get the patients done, but of course the numbers; if the numbers are that big, then it becomes hard, we can't handle.

Interviewer: Let's look at health information and medical records system place, how is it? How records are kept and are you happy with that? How is that working for you? In case you need to access information on the system, can you easily get it?

Respondent: Actually it's hard to trace the old note, um, but we have been assured we are upgrading to system to be electronic. That's what we have been assured but of recent, accessing old files is hard.

Interviewer: Do you have specific registers for ARF and RHD here?

Respondent: no.

Interviewer: Do you specific registers for certain diseases here?

Respondent: Um, all registers are integrated kind of registers. Like SGBV, HIV; integrated kind of.

Interviewer: okay. Do you have guidelines and protocols for RHD care in this hospital?

Respondent: I have not come across any. [Laughs]

Interviewer: Would they be important?

Respondent: Yes, I think so.

Interviewer: Why do you think so?

Respondent: To avoid missed opportunity; we end up treating malaria! Someone has a fever, yes probably its malaria, but if the guidelines are there, one would take a further step. If I have treated these fever as malaria or UTI and probably the symptoms are persistent, and maybe this one has a history of a sore throat, then the aggressiveness in management probably would be . . .

Interviewer: okay. Then, do you have a proper referral pathway for our RHD patients here?

Respondent: um, we actually manage them on timely limit and probably pediatric ward.

Interviewer: and if you can't handle them here, then what do you do?

Respondent: [sighs]

Interviewer: now, from all the pieces we have talked about, you can tell me what you agreed to. With administration and the leadership in the district, you didn't know even what their role is!

Respondent: [laughs]

Interviewer: funding, that didn't work for you, funding for health care; health worker numbers?

Respondent: No.

Interviewer: Medication?

Respondent: Medication particularly with Benzathine, we have not had shortage with that.

Interviewer: um, the health information system, that one is lacking.

Respondent: Yes.

Interviewer: then the guidelines and protocols, those are also lacking.

Respondent: Yeah.

Interviewer: Then, anything else that has motivated you to work; you still care for your patients despite all the challenges?

Respondent: what has motivated me! It's my job to care.

Interviewer: okay. Last set of questions. So I would like to know about your perception about patient outcome; generally do you think our patients get the care they need here?

Respondent: Generally yes. Why yes? Um, the specialized consultants are available to make the right diagnosis. Where we are handicapped is usually on the investigative part; laboratory and radiology. That's where sometimes the challenges are because of logistics.

Interviewer: because of logistics!

Respondent: Yes.

Interviewer: And um, in case a patient needs surgery here?

Respondent: if a patient requires surgery, probably not. We have not had any cardiac surgeries performed here.

Interviewer: Do you have any patient safety and quality of care concern as you?

Respondent: Patient safety?

Interviewer: Yes, where you feel like your patients are safe or they are handled in a safe way? Do you have some concerns or the quality of care?

Respondent: There are concerns but the concerns are probably policies and the quality of care is not that good.

Interviewer: okay, and you said it's because of the?

Respondent: The infrastructures, utilities, and the supplies.

Interviewer: okay. Have you witnessed any preventable deaths in the hospital here? You feel like that death shouldn't have happened?

Respondent: yeah I think so.

Interviewer: What was the scenario like? What could have happened?

Respondent: A scenario was um, lack of space in the theatre, and we kept on telling this patient that "we can do you after this or after this other case." or "Let's do you after this case"

Interviewer: And the patient passed away!

Respondent: Yes, and the patient passed on after he had been put on the table, but I think there were a time lag.

Interviewer: Do you think our patients are dying in the community without presenting to the hospitals?

Respondent: I think they are. There are places where transport is really hard to get to the health center and if they are to go to the health center, the referral system is hard, and they reach the health center when it's even late. By the time they are told that we are sending you to the referral hospital, then they have to go back home to look for what to transact to get money to bring them to the hospital. It's hard.

Interviewer: last question; in your opinion, give me one or two most important things Ministry Of Health should do to improve the patient outcome?

Respondent: Increase on the human resource.

Interviewer: Which carders mainly?

Respondent: The nursing carders. Now for Mbarara, it's a little different; we have both Ministry of Health and the University. So with the university at the doctor's level, probably we are covered somehow but for the nursing side, we are not covered.

Interviewer: That's one.

Respondent: and probably the infrastructure; this being a regional referral which was constructed in 1953, it cannot match with the current numbers. And the disease burden, of course the trends have changed. In Mbarara, the means of transport is mostly motorcycle, so there are a lot of accidents and we need actually a separate complete unit for neural as well.

Interviewer: okay, anything else before we stop?

Respondent: Budget cuts are also doing us bad. If the government would follow the Abuja Declaration and meet the 15% declaration of which Uganda is also a signatory, probably it would do us good.

Interviewer: it will do you good!

Respondent: Yes.

Interviewer: Okay. Thank you very much, we appreciate so much your feedback that you have given, and we shall use your data with other health workers' to see how we can improve care for our patients. Thank you so very much.

Participant ID	HW 005 -Mbarara
Date	8 /Nov/2019

Interviewer: Today is the 8th of November 2019 and we are seated here in the cardiology room at Mbarara Regional Referral Hospital and this is participant 005. So we use what, English?

Respondent: Yes.

Interviewer: Okay. Thanks for allowing to speak to us today and just to remind you a little bit, we want to determine how we can provide better care for our RHD patients. There are no right or wrong answers so be frank and share your opinions, and the data we gather is going to be confidential; we will not link your identity to any of your comments in any of the reports we produce. So please tell me about yourself; how old are you?

Respondent: I am [REDACTED] years old.

Interviewer: [REDACTED] years old. And what are your qualifications?

Respondent: I am a [REDACTED].

Interviewer: Where did train from?

Respondent: From [REDACTED].

Interviewer: And how long ago did you train?

Respondent: For [REDACTED] years.

Interviewer: How long ago? Which year?

Respondent: I went there in [REDACTED] and then I started working here in [REDACTED].

Interviewer: And then, eh, [REDACTED]! Those are how many years?

Respondent: Many.

Interviewer: Okay, and then um, in your practice, when you look at the demographics of your patients, what are the common illnesses that you treat? What kind of patients have you been seeing over the years?

Respondent: I have been seeing diabetic patients, hypertensive patients, and cardiac patients.

Interviewer: Mainly, when you look at the sex, which patients do you see?

Respondent: Mainly females.

Interviewer: Why females?

Respondent: As you can see according to our ward, women are always many on their side than males.

Interviewer: And then the age groups, which ones do you normally see?

Respondent: From 50 years and above. Those that are diabetic, hypertensive patients, those with stroke and the young age, they are always . . .

Interviewer: What are their illnesses, the young ones?

Respondent: HIV for most of them.

Interviewer: The children?

Respondent: Yes.

Interviewer: Okay thank you. Now, tell me a little bit on your training in RHD. Have you received any specific training during school?

Respondent: We trained in both, anyway we trained. They trained us in many conditions.

Interviewer: Was it part of it?

Respondent: Yes it was there.

Interviewer: Was it there? RHD?

Respondent: Yes, it was there also

Interviewer: Was it in school or after school?

Respondent: It was after school when I started seeing those patients with RHD.

Interviewer: You got trained!

Respondent: Yeah.

Interviewer: Who trained you?

Respondent: I was trained by, umm, he was called

Interviewer: He was a what?

Respondent: That was a principal tutor.

Interviewer: And where did you train from? Where exactly was your training?

Respondent: In Kabale hospital.

Interviewer: Okay. And then um, how often do you see RHD patients?

Respondent: These days?

Interviewer: Yeah

Respondent: Not often but sometimes they come.

Interviewer: How many can you see in a week?

Respondent: In a week, like 2.

Interviewer: 2 in a week! Are they usually outpatients or you see inpatients?

Respondent: In patients; they're admitted and then we see them on the ward.

Interviewer: Now I am interested in what you have been taught about RHD. What do you understand to be the cause of RHD, in your own view?

Respondent: That one can be caused by very many things.

Interviewer: Like which ones?

Respondent: Like when a patient falls sick and doesn't come immediately to the hospital to go for checkups.

Interviewer: Like when they have fallen sick, which disease would that be?

Respondent: Like malaria, like when someone is having chest pain, that body swelling, palpitations and difficulty in breathing.

Interviewer: Okay, and then, are you aware about the link between sore throat and Rheumatic Heart Disease? Are those 2 related?

Respondent: They are related.

Interviewer: How?

Respondent: Of course when somebody suffers from sore throat, at times you get what, um, that one can also bring difficulty in . . . [inaudible].

Interviewer: What were you told can be done to prevent Rheumatic Heart Disease?

Respondent: Anyway, for that one you go for a checkup and the doctor is the one to decide what . . .

Interviewer: What?

Respondent: What to do to the patient and what treatment you should be given.

Interviewer: Okay. What were you taught are the treatment options for RHD? Which are the different treatments of RHD were you taught?

Respondent: RHD, you know sometimes they come with that difficulty in breathing, body swelling, heart palpitations; that one we usually give. Like for body swelling, we usually treat with IV Lasix, we give digoxin tablets and they include antibiotics.

Interviewer: Okay. Apart from that kind of treatment is there options that is there?

Respondent: yes, they do some investigations like ECHO, ECG and chest x-ray at times.

Interviewer: Okay. So what is your understanding about the long term prognosis of RHD?

Respondent: It is like that the patient can get what . . . those are patients who get cardiac . . .

Interviewer: And then, tell me about your encounters with patients who had RHD? So the last one, you said each week you get like 2?

Respondent: Yes.

Interviewer: Okay. So when did you last see a patient with RHD?

Respondent: Was it last month?

Interviewer: That's when you saw that patient!

Respondent: Yes, last month.

Interviewer: So briefly summarize the visit for that patient. How did that patient present? What was happening?

Respondent: Anyway the patient presented with body swelling, he had difficulty in breathing, heart palpitations, and he was restless . . .

Interviewer: What happened when he came? How old was that patient?

Respondent: 19 years.

Interviewer: Boy/girl?

Respondent: A boy.

Interviewer: So what happened when that person came?

Respondent: When he came we started with investigations then after that...

Interviewer: So he had not been diagnosed already with RHD?

Respondent: Any way I asked the mother whether they have ever visited you here and they told me that she has been coming bringing that boy. Then until he was admitted on the ward.

Interviewer: Okay. So um, the RHD patients you see, what is the average age?

Respondent: Age? I have seen one of 16, 19 and 23 years of age.

Interviewer: Those were the ages?

Respondent: Yes.

Interviewer: Are they in school or out of school?

Respondent: That one whom I saw was in school.

Interviewer: Okay are they generally aware of the link between sore throat, Acute Rheumatic Fever and RHD? Do you think our patients know?

Respondent: They know only when they come here but when they are not yet here at the hospital, they don't know what's happening. For them they think its sore throat.

Interviewer: So you have told me the symptoms they usually describe to you, you said chest pains, joint pains . . .

Respondent: Joint pain is also included.

Interviewer: Okay, and what else?

Respondent: Heart palpitations, body swelling.

Interviewer: Okay and then, are they good at follow-up and adherence? Do our patients come back for follow up?

Respondent: Yeah, they come.

Interviewer: All of them?

Respondent: Yes, they come. After discharge they give them a return date they come.

Interviewer: What motivates them to come?

Respondent: [scoffs] it's the day which you have given them, so at the end they have to come back.

Interviewer: Because we have seen in some cases where people are given a day to come back but they still don't come back.

Respondent: There are some people that don't care but when you care about your health or your kid's health, you have to come back for checkup.

Interviewer: Apart from not caring, which other reasons?

Respondent: Transport, money.

Interviewer: Is transport a lot for some of them?

Respondent: Some of them come from far districts like Lyantonde, Masaka, Kyengwegwa, and Kasese . . .

Interviewer: They all come here?

Respondent: Yes, we have people from Kisoro, Kabale . . .

Interviewer: Why do they come here?

Respondent: At times it a referral and this is a referral hospital. So they are referrals from that end.

Interviewer: Okay and then um, but the ones you see you said they come back usually!

Respondent: Yes they usually come back on the return date.

Interviewer: And the reason you have given for that answer is because you said the parents care.

Respondent: Yes, parents care; the mothers.

Interviewer: Apart from caring parents, what else could be a factor when they come back?

Respondent: They come back to see their doctors so that they do what . . . when there medication which they were given is over, they have to come back for more.

Interviewer: Okay and then, have you seen some who were maybe given an appointment a month after getting the initial treatment and they come back after 4 months?

Respondent: Yeah they come.

Interviewer: After 4 months and yet they were a given a follow up of 1 month?

Respondent: For one month?

Interviewer: Yes.

Respondent: They come.

Interviewer: Now when they come back what do they tell you?

Respondent: Now what you do? They tell you reasons; "I didn't have money for transport." Transport majorly is the problem.

Interviewer: Transport is the problem!

Respondent: Yeah, but you have to treat them.

Interviewer: okay. How about adherence to drugs, do they adhere? There's coming for follow up and getting the drugs but someone doesn't take them.

Respondent: For those 4 months when the drugs are over, they remain like that.

Interviewer: How about those who come, I mean those who stick to their appointment; do they still adhere to the drugs that they are given?

Respondent: Yes.

Interviewer: What would motivate them to even come for the painful injection like some people say and take all the drugs that they are given?

Respondent: You want your health to do what, to be healthy and not to fall sick each and every time.

Interviewer: Okay. Now let's look at the local health system barriers. I would like you to tell me the pieces that you feel are working for you among the ones I have on the list and those which are not working for you. Let's begin with administration here, is it working for you in terms of your work with your patients?

Respondent: Yeah.

Interviewer: Yes?

Respondent: Yes, they do.

Interviewer: Why do you say yes? What makes you feel like "yeah!"

Respondent: At times some hospitals don't have drugs, they complain about that and that, but for us here, drugs are on time and the moment they are over, they have gone for more drugs. The sundries.

Interviewer: Okay. How about the leadership in the district?

Respondent: Also the leadership, they are trying; we have no problem.

Interviewer: What do you feel like they have done for you? The leadership, DHOs how are they supporting you in your work?

Respondent: They are supporting us maybe in terms of . . . they give us uniforms, and other resources.

Interviewer: Okay, thank you. Let's look at the funding in general. How is it to you? Is it working for you?

Respondent: The funding is okay.

Interviewer: Why do you feel like its okay?

Respondent: You know sometime time back, they increased our salaries [laughs].

Interviewer: They increased?

Respondent: Yeah, that's why I am saying it is okay. At least our salaries where increased.

Interviewer: Yes. How has that increment impacted on your work?

Respondent: when you have that motivation, you also have courage to work hard and look after your patients.

Interviewer: How about funding for RHD care, how is it here?

Respondent: For that one, huh! For that one I think it depends.

Interviewer: It depends on what?

Respondent: When somebody (patient) doesn't have some resources, some doctors can do some funding and they help them in each and every one.

Interviewer: Let's look at the health workers, how are the numbers? Are you working with them? Are the numbers and qualifications working for you?

Respondent: For numbers, as we have been talking we are really few.

Interviewer: Which cadres are really very few?

Respondent: The nurses are not many.

Interviewer: Are the doctors many?

Respondent: The doctors are many. They are there but for us the nurses, no.

Interviewer: You are very few!

Respondent: Very few!

Interviewer: Okay how about the qualifications! When you look at the staff, are they qualified for the work they are doing?

Respondent: Yes.

Interviewer: Do you have the different qualifications that you need in the hospital?

Respondent: Now which one?

Interviewer: Like when you have RHD patients, um, those who need surgery, can they access surgery here?

Respondent: Not here. They cannot.

Interviewer: Okay. So let's look at the waiting time for our patients, how is it?

Respondent: For those with RHD?

Interviewer: Even the general patients. How much time do they spend? What do you have to say about the time they spend at the hospital when they come for treatment?

Respondent: Anyway, some of them they spend few days.

Interviewer: The outpatients?

Respondent: For the outpatients, you know they are many.

Interviewer: Is the time reasonable according to you?

Respondent: By the way time is reasonable because the doctors come early and see them. When you are supposed to go to the laboratory, you go there and when you are supposed to get medication from the pharmacy, you go and get it.

Interviewer: Okay. How about the quality of care, how do you look at it? The quality of care you give to your patients.

Respondent: It is enough because we are there for them each and every time. When you are on duty, you have to be with them until you leave. You start at 8am you leave at 2pm. At night you are with your patients and also in the evening.

Interviewer: So quality of care to you is okay?

Respondent: It is okay.

Interviewer: How about the medication? Let's look at the medication for the, like the anti-coagulation, heart failure drugs, BPG, how are the stocks here? Are they available?

Respondent: Yeah they are available.

Interviewer: Any issues you have with the drugs? The stocks?

Respondent: They are available and when they are not available at times, we tell them to buy. But they are always available.

Interviewer: Okay, so those times you tell them to buy, do they get any problems with accessing those drugs? They don't.

Respondent: The pharmacies are here.

Interviewer: How much do they pay for . . . would you be knowing how much they pay? Like for an RHD patient who has been referred outside to go and buy some of the drugs?

Respondent: You mean at the drug shops?

Interviewer: Yes

Respondent: I have never asked them but most of them get the drugs from around.

Interviewer: How about the diagnostics, the ECHO Cardiography?

Respondent: That one is free.

Interviewer: It is free of charge! And you have it here?

Respondent: Yes, it is free.

Interviewer: Other diagnostics, any that you feel are missing?

Respondent: Chest x-ray.

Interviewer: Okay, and then let's look at the health information and medical records systems in place. How are they when you look at them?

Respondent: The what?

Interviewer: Medical records system and health information system. Is it working well?

Respondent: Yes.

Interviewer: Why do you say it's working well?

Respondent: When we admit the patients on the ward, then we have our . . . where we admit our patients. Usually when they come from medical emergency, we have to register our patients and when they are discharged, we have to record them also to be discharged. Then after discharging them, the records officers come for those files and take them.

Interviewer: So if a person came in 5 years from the last time you saw that person and you need that file, is it easy to access it?

Respondent: Yes.

Interviewer: Okay. So you feel like the health information system and medical records system is working for you?

Respondent: Yes.

Interviewer: How about um, do you have registers for Acute Rheumatic Fever and RHD here? Do you register them separately?

Respondent: For us here on medical, we register them in the same register.

Interviewer: Do you have guidelines and protocols for RHD care here? Is there a protocol you are following as regards to RHD care?

Respondent: No.

Interviewer: Or guidelines. Have you ever looked at them?

Respondent: Yeah, I have ever looked at them.

Interviewer: Where do you keep those guidelines and the protocols?

Respondent: In the sisters' room and others are in their ward. You know we have that ward, that cardiology ward; it is always has all the guidelines written there about what they should follow what to do to care for those patients.

Interviewer: So from the list we have gone through, um, in my understanding from what you have told me, the administration is okay.

Respondent: Yes.

Interviewer: You are fine with it? It's working for you?

Respondent: Yes.

Interviewer: Funding for health care?

Respondent: [scoffs]

Interviewer: You said your salary was raised!

Respondent: Yeah, it was a bit raised.

Interviewer: So is it working for you?

Respondent: Yeah. That one is.

Interviewer: The health worker numbers, is that working for you?

Respondent: Yes.

Interviewer: You have enough staff?

Respondent: Staffing is not enough.

Interviewer: So that one is not working for you. Medications?

Respondent: Medications we get.

Interviewer: You get them. And the health information and medical record system you said?

Respondent: that one is okay.

Interviewer: For the guidelines and protocols for RHD care?

Respondent: Yeah

Interviewer: Now, as we are about to wind up, let's look at your perceptions of patient outcomes. Generally, do you think our patients are getting the care they need here?

Respondent: yeah, they get care because they can come, we admit them and they are discharged when they are okay.

Interviewer: They are fine!

Respondent: yeah.

Interviewer: How about the outpatients?

Respondent: outpatients! Outpatients also come and be treated. Anyway, when they are on injectable like Ceftriaxone and what, for the days that they have given you, you have to keep on coming and those who have malaria and such illnesses, you go the pharmacy and get the medicine.

Interviewer: They get the medicine!

Respondent: Yes

Interviewer: Okay, so um, how about those who need surgery, can they access it here?

Respondent: Yeah, some of them.

Interviewer: You have had RHD patients who have had surgeries here?

Respondent: No, they are referred to Mulago.

Interviewer: Okay. So do people know the referral pathway? Do you have a path you follow when you are referring them?

Respondent: Yes.

Interviewer: Is it known to the health workers here?

Respondent: Yeah.

Interviewer: Okay. And then do you have any patients' safety concerns and quality of care concerns? Personally, when you look at the patients' safety and quality of care, do have any concerns on their safety and quality of care concerns?

Respondent: My concern is that, hmm; these patients suffer a lot. When they tell you to Mulago for surgery when you don't have money, or they tell you to go to India, and really they suffer a lot.

Interviewer: They suffer!

Respondent: They suffer a lot.

Interviewer: What do you think can be done for these people so that they don't suffer a lot?

Respondent: We should be having our own things; machines.

Interviewer: Machines which do what?

Respondent: The heart . . . [laughs] yeah

Interviewer: The heart machines?

Respondent: Yeah

Respondent: Then our patients will not suffer going to India.

Interviewer: So have you witnessed or do you feel that there are some preventable deaths which are occurring in the hospital?

Interviewer: no yet.

Interviewer: There is none that you have heard of?

Respondent: no.

Interviewer: And then, do you think patients are dying from the communities without presenting to the hospitals?

Respondent: Yeah, they die. Others when they fall sick, they tell you, "You are being bewitched." They are threatened that don't take to the hospital while others are taken to churches. Even here; they take the patient away from the ward claiming that they are going to pray for him!

Interviewer: Okay. So in your opinion, give me one or two most important things that Ministry of Health should do to improve our patients' outcomes.

Respondent: If possible, they should bring each and everything near to the hospitals. Like in a referral like this one, we should get that machine nearby so that when we get those patients, at least we work on them. But they are not there.

Interviewer: Anything else?

Respondent: Yeah, and when they bring that machine, it should be free not to tell the patients to pay this or that so that they could be worked on.

Interviewer: Okay. Anything else before we wind up?

Respondent: –no response-

Interviewer: Nothing?

Respondent: No.

Interviewer: Thank very much.

Respondent: Thank you too.

Interviewer: Thank you for that information that you have given me, it will help us to see come up with a strategy to improve the health care for RHD patients. Now I will hand you over to [REDACTED] to give you

Interviewer: Thank you also.

Participant ID	HW 006 -Mbarara
Date	9 /Nov/2019

Interviewer: So today is the 9th of November 2019 and we are seated at the doctor's plaza and we are interviewing participant WH006. Okay, so thank you for giving this time to talk to you. Just to remind you a little bit is that we are looking for different ways we can improve care for our RHD patients and there are no right or wrong answers, what we are interested in are your views. So we ask you to be frank and share your opinions with us. Your data is going to be kept confidential like we told you and we are not going to link your identity in any of the reports we produce. Can we go ahead?

Respondent: Yes please. It's okay.

Interviewer: Can you tell me a little bit about yourself, how old are you sir?

Respondent: I am [REDACTED] years.

Interviewer: And what are your qualifications?

Respondent: I have [REDACTED].

Interviewer: Okay. Nice to meet you.

Respondent: Nice to meet you too.

Interviewer: Okay, so where did you train from?

Respondent: In [REDACTED].

Interviewer: How long ago did you qualify?

Respondent: [REDACTED].

Interviewer: Wonderful. So when you look at the demographics of the patients in your practice, what are the common illnesses and who are these patients you see?

Respondent: Well it's hard to tell but they are so many patients. Well, for me in my line of specialism I tend to see more of non-communicable diseases although when I am doing general, I see a lot of HIV, malaria, streptococcus, TB. But in my area of specialization I do a cardiology clinic, so I see a lot of heart failure, hypertension, RHD and diabetes.

Interviewer: Okay. Wonderful. So by age group which is the . . . ?

Respondent: By age group the majority I see are in the youth bracket and a few elderly ones. Especially for the non-communicable diseases, I see elderly ones with heart failure and hypertension. But for these other diseases of RHD, they tend to be any age but majority between 20 and 40 years.

Interviewer: 20 and 40, for RHD!

Respondent: Yes but I have seen elderly with RHD.

Interviewer: Okay. Then those ones with RHD, are they school or working. The majority.

Respondent: The majority, I cannot point majority because I would have to have figures to know whether it is the majority, but I can say many of them are in school and also a good number are not.

Interviewer: Okay. So let's talk a little bit about your training in RHD; have you received any specific training during school?

Respondent: Yes, I received training during a cardiology fellowship about RHD, and I have run with colleagues RHD clinics at the heart institute and also here. So that's the basic training that I got.

Interviewer: Wow, that's good. So where did you train from?

Respondent: Like I told you, Mbarara University for Bachelors and Masters. Then I went to Uganda Heart Institute in Kampala where I studied most of the RHD knowledge that I have.

Interviewer: So how often do you see RHD patients? Is it per day, a week? How many can you say in week?

Respondent: In a week I see like 2.

Interviewer: Like 2. Do you see outpatients or inpatients?

Respondent: Yes, most of them are outpatients.

Interviewer: Okay that's good. So I am interested in what you were taught, what are the causes? What do you understand to be the causes of RHD?

Respondent: I understand streptococcus to be the cause of RHD and I also understand that it comes usually during early childhood like 3-5 years, teenage; early exposure to sore throat. So what I know is that the sore throat usually the one which is streptococcus maybe treated insufficiently or maybe go away on its own but there's an element of molecular mimicry. Like to simplify it, the immune system of an individual will recognize with infection and try to fight it, but what I might call a body accident; the body will also produce a mechanism which will target other organs accidentally. So mostly, it will target the heart valves. Remember it was trying to clear the sore throat but many years later, the immune response attacks the valves of the heart, but it can also attack the joints and brain. So that's what I know as the cause.

Interviewer: Okay. So you have answered my next question, I will not ask it. So what can done to prevent RHD?

Respondent: Quite a lot of things but the first one is to promptly diagnose and treat sore throat and treat it adequately with penicillin. But that is treating a case, and then the other thing is to prevent cases. One of the things is to avoid overcrowding of our children especially kids at school; nowadays they crowd in one room like this one. You find like 20 kids in a dormitory and if one has a sore throat and it is contagious and they will all get it. So reduce congestion and reduce poverty levels as well because if there was no poverty, children would be brought for screening for sore throat but because of poverty, they don't.

Interviewer: They don't bring them!

Respondent: Yeah

Interviewer: Okay and then what were you taught are treatment options for Rhd?

Respondent: The first treatment is usually penicillin. Yeah Penicillins. Whether you give them PEN-V but we would want to see what stage is the RHD; how much has it done so far? So we would do an ECHO, a simple scan so that I can see that really is the RHD there? Is it mild or it is severe? How many valves are involved? Is the patient in heart failure or not? So from there, you make a decision; if it is mild or if there are early changes, because there are also early changes, what we call early rheumatic changes. When you do an ECHO it could be that. Then that one is a case of follow up; you advise promptly to treat the sore throat. Okay?

Interviewer: Yes.

Respondent: Or you give some shots of Benzathine penicillin, they will come back and you repeat the ECHO, and interestingly, some of them regress. You find those changes have gone back in the very early stages.

Interviewer: Wow.

Respondent: But when you have an established disease, now that is a permanent diseases, a severe one because heart failure will need medicine for 3 things; the first one is to prevent recurrent sore throats to make sure you don't get more injury. The next one is to treat heart failure in case people have heart failure or prevent changes, what we call remodeling of the heart, the heart may dilate or fail. Or those who are already in heart failure, you treat heart failure. But ultimately, they need surgery, those who are already severely sick they need surgery to correct the valve or replace it. You put a new valve.

Interviewer: Wonderful. Wow! So what is your understanding about the long term prognosis of RHD?

Respondent: If caught early, if the disease is diagnosed early the prognosis is good actually, I told you some may regress. But here in our experience, majority are discovered late, the prognosis unfortunately is not good; it is very bad. We have a lot of cases where you can't do much and they can't afford surgery or they're too late for a new valve. You know even putting a new valve, when you are too late, you will not even be managed.

Interviewer: Why are they coming late?

Respondent: It is because of challenges with diagnosis. As I told you, it is not easy to link this sore throat to the problem of the heart. Even majority won't know that they had a sore throat. Imagine if you get a sore throat and you are 3 years old, or 5 or 10 years old and it goes away, so now they come in with non-specific symptoms and they are in the village and there is not enough knowledge about it, so they are in heart failure, they're having chest pain palpitations and they are lost. They are treated by many people because not everyone has ECHO to see what's in the heart and the symptoms could be because of many things. So the diagnosis is usually delayed.

Interviewer: It is delayed!

Respondent: That's the main problem.

Interviewer: Wow. You have said they don't have the knowledge, how can we step up the knowledge?

Respondent: There are efforts already which have been made; we have had schools' programs for sensitizations and also a bit of checkups to see how many. There was a study which was run around here. So there is some knowledge around here in schools.

Interviewer: Okay.

Respondent: Then there has been some campaigns, a few ones on radios right now and there's also an advert going on to screen for Rheumatic Fever. So giving such knowledge generally improves people to start thinking about the heart and what can go wrong.

Interviewer: Okay, that's wonderful. So do you remember the last patient you worked on for RHD?

Respondent: I remember.

Interviewer: So how long has it been?

Respondent: Yesterday.

Interviewer: [laughs] could you briefly tell us how that visit was? Who was it?

Respondent: It was a follow up visit and it was a good news of RHD regression.

Interviewer: Wow.

Respondent: Which I don't see many times, so this was mild Rheumatic Heart Disease with mild micro gurgitations. It was diagnosed this year in January, so I followed up after 6months so that was July there, the symptoms had reduced but we still maintained PEN-V penicillin. So the patient came back yesterday and we did another ECHO, and RHD changes on the heart had disappeared.

Interviewer: Wow. How old was this?

Respondent: This was a 30 year old lady. It is one of those which am very proud of.

Interviewer: Wow, that's wonderful. So do these patients know the link between sore throat, ARF and RHD, at all? Do they have a sense of, do they know that?

Respondent: The ones who come to us are referred via ELT doctors here. The unit doctors explain to them that "you have recurrent sore throat so you could be having RHD, so go to physicians, cardiologist or whoever for further screening." Those ones come knowing and they are the ones who usually comply to treatment very well. But the ones we diagnose usually who come in late, they don't know actually.

Interviewer: They don't!

Respondent: So the majority don't know.

Interviewer: They don't even know that.

Respondent: Yes.

Interviewer: Okay. What sort of symptoms do they usually describe to you when they come?

Respondent: They come with easy fatigability, (they get tired).

Interviewer: Yeah, they get tired all the time.

Respondent: Body swelling, they come with chest pain, they come with palpitations, so those are the four main symptoms. But there are those who come with a cough that is not going away; they have treated the cough and it is not going away but when you check the heart, you find the problem is from the valves.

Interviewer: Okay and are they good at follow up and adherence?

Respondent: Yes and no, and it varies from patient to patient. So I will categorize them.

Interviewer: Okay.

Respondent: I will say the ones who have support like social support, family support come back and the ones who are alone don't come back. I have seen that case clearly.

Interviewer: So social support like what?

Respondent: Social support makes them comeback but without that, they go away and they get lost, and then we discover them on the ward in heart failure admitted.

Interviewer: Oh! They come back when . . . ?

Respondent: Yes. When they are very sick and in heart failure. So you say "eh! This one was our patient of RHD."

Interviewer: So part form social support, what else makes some people comply with the drugs?

Respondent: Well, when they have pain, unfortunately, when they have pain they keep coming and complying for that period when they are in pain, with bad symptoms, but as they get better, they disappear then they come back when the symptoms come back. That is what I have seen.

Interviewer: Okay. And then um, so to then when they come back especially in heart failure, what excuses do they give for having not come back?

Respondent: The medicines. You see the medicines in the hospital, some are there and some are not there. Those who are not in the RHD program may not get and for me I also work in private sectors and other places, so there the medicine is expensive.

Interviewer: So it's the medicine.

Respondent: The medicine is expensive! So they take. Then others get tired of medicine because it is daily, then the injection is painful. This Benzathine penicillin is terrible, you know it.

Interviewer: Yes.

Respondent: it's like the one of syphilis if you have ever got it, and it is terrible, very terrible! And the technique of injecting, not every nurse knows it. So some nurses, sorry to say, inject it badly or poorly or they don't put pain killers or Lignocaine there. So the patient says "ah, I am not going back for that painful injection"

Interviewer: Okay. And then um, now let's look at the local health system barriers that you are facing. You are going to tell me which ones are working for you and you tell us why and those which ones are not working for you and you tell us why?

Respondent: Yes.

Interviewer: Let's look at the administration and leadership in the district, is it helping you do your work with our patients?

Respondent: I don't know much about the administration at the district.

Interviewer: You don't know?

Respondent: Yeah, I only know the administration at the hospital. Because a regional referral hospital is semiautonomous; we are under the central government, Ministry Of Health more than the district. We seem to be above the district; the DHO I think doesn't have a lot of say, so I don't think . . .

Interviewer: Okay. So let's talk about the administration in the hospital.

Respondent: It is very good.

Interviewer: Is it supportive?

Respondent: Yes it is because working together with the heart institute, it is the one really responsible for the cardiology clinic together with the university. So heart institute, Mbarara University, MarieStopes and Ministry Of Health. So there's coordination really; it is the same angle that we managed to the ECHO machine. It the ECHO which does a lot of diagnostics, you see that? Then there's an RHD program. So our place is organized because we have a specific RHD clinic on Fridays and then we also a general cardiologist clinic in Tuesday. So if a patient comes when it's not a Friday and they are sick, they can still be assisted. So the system is good.

Interviewer: Wow, that's wonderful. Now when you look at the funding of health care, how is it? Is it working for you?

Respondent: I don't know much about funding for health care but what I can say, salaries are paid on time.

Interviewer: That's good!

Respondent: So I have no reason to say in that regard, well maybe the drugs; if some patients may not get the heart failure drugs, then that may be an issue.

Interviewer: Are they getting them?

Respondent: They get some like Lasix and Captopril but if you want more, others you might not get them like the Losartan. But if you want Atenolol, captopril, Lasix you will get. So I could say it is 50/50.

Interviewer: 50/50. So for those they cannot get at the hospital, how much can they spend for a month?

Respondent: Unfortunately, the drugs which are not available are the most expensive ones. So the ones that are on are what we call the essential drugs from the Ministry. They may not be very efficacious for these cases who are in heart failure, so you may want to bring back the injection fraction, blah. So if they have to buy, it is very expensive.

Interviewer: Like how much?

Respondent: They can spend like 100,000shs a month if they are in heart failure. That's a lot of money, 100,000shs seriously! It is a lot. It is actually more than 50% of their earnings because if you take the earning of people here, it is like 200,000sh-300,000shs.

Interviewer: Okay. So what do you have to say about the funding of RHD in general? In particular.

Respondent: Funding of RHD it is lacking, I am sorry to say. Because, we should look at it in a holistic way, now there's RHD clinic, we won't go into the details, but what if the RHD research clinic closes? Because like any other project, it has a timeline, it has to close, what will happen? These patients will fall back to the general cardiology all of them and the medicine which we are getting for RHD, the follow up and sometimes the phone calls to bring them back, I don't know about transport refunds but I know about phone calls and follow up will be lost. So the funding should be sustainable, what I see is there right now it might not be sustainable. So funding is not enough.

Interviewer: Okay. And let's look at the health worker force, how are the numbers and qualifications that you have?

Respondent: The numbers now and qualifications, we have 2 physicians with some cardiology training with one in the cardiac patients' clinics. It's fair for now because when you are 2, one can even afford to be off today, this week and the other works or you work together one on the ECHO machine and the other treating the patients. For now, it is okay but it also because of the help of RHD (study), the second clinic will close as soon as the RHD clinic study stops. Then in terms of other cadres, we also have senior health officers, doctors who are trying to specialize in internal medicine, they help us. Because we have taught them so they help us. Because this is a teaching hospital, I think the workforce is good for the doctors.

Interviewer: Waiting time for our patients?

Respondent: Waiting time for our patients varies; if we have many patients in the line we prioritize those ones who are very sick. So whether you have RHD or not, if you are very sick you will be seen. So waiting time will be on average about an hour. Unfortunately, if are dealing with an RHD case, it takes a lot of time on the ECHO machine; it is a tedious exam but if I am dealing with hypertension, 10 minutes and I'm through.

Interviewer: You are done!

Respondent: Yeah, but to study a valve in an academic way because we are in a teaching institution, it will you take a lot of time.

Interviewer: It takes a while!

Respondent: So the next patient to come after one rhd patient, it will be about minimum of 30 minutes and maximum 1 hour.

Interviewer: Okay, thank you. And then when you look at the quality of care that you are giving to these patients, how is it?

Interviewer: On average, it's above average. Reason being this being a teaching hospital, I think we tend to follow protocols so it's above average. We may lack some few things but it's above average here.

Interviewer: It's above but it's not yet there at 100.

Respondent: It is not at 100 because of patient numbers.

Interviewer: Okay.

Respondent: So sometimes you have to wash through and finish the line, so there you don't do what's the ideal. You just do the basic that you can and that will be above average.

Interviewer: So what is that that you can't do especially on busy days when you are working?

Respondent: On busy days you may not do a full ECHO.

Interviewer: Okay.

Respondent: You may do just a basic ECHO and that one affects quality. Let's say if you are studying micro valves, you want to see in details how much RHD has done to eat from the base to the valves themselves to the tips and surrounding areas and you score, you do what is like a weekly score. But when you are in a hurry, you just say severe Mitrosclerosis and you put micro valvular ending.

Interviewer: Without scoring!

Respondent: but you do not score; you be like, "I want to finish" because it takes a lot of time. You may not calculate the Pulmonary Pressure because it takes a lot of time but you must see severely, this rheumatic and it is schiznosed. We diagnose and you just go. So that is slightly average above average and not ideal. The other thing which might be lacking is patient education; so we shall do diagnosis and send to the nurse to treat or to dispense the treatment. But if we had few patients, we would sit with the patients and say "look, we found this and is because of this." So if a patient hears it from the doctor and they may believe it better. And I don't know why, but they tend to believe it better when they hear it from the doctor than a nurse or a second person that simply says, "The doctor said ABCD."

Interviewer: Okay, wonderful. Let's look at the medications; how are the stocks?

Respondent: I really don't know about the stocks.

Interviewer: Anti coagulation, the heart failure drugs?

Respondent: I want to tell you that I don't know about the stocks.

Interviewer: Yes.

Respondent: We write and you go get or don't get. So we don't know.

Interviewer: Eh, So you don't know much about that.

Respondent: Yes.

Interviewer: But for the diagnostics you said have said you have that.

Respondent: We are doing well; we have ECHO which can do a detailed study of what you want.

Interviewer: Are they paying for the services?

Respondent: If they come among the general patients they pay. If they come among the RHD study they don't.

Interviewer: So for the general, how much do they pay?

Respondent: For the ECHO?

Interviewer: Yes.

Respondent: They pay 70,000shs

Interviewer: Okay. Can many afford that and what do they do when they can't?

Respondent: Well they complain but if they are really poor, there's a waiver that comes out of bureaucracy to the hospital to waive. So they can't afford in general because 70,000shs, and I told you already 100,000sh is a much. So 70,000sh is close to 100,000shs. It is not really affordable but they struggle.

Interviewer: Let's look at the health information system you have and the medical records systems, how are they?

Respondent: Well again I say that for those who are in study, the information is good.

Interviewer: Why?

Respondent: Because they have the papers that are already pre-signed to get the information that you want and there's a channel of information to even consult work to get and follow. That one among the study, they are good. Those ones who are not in the study, the general cardiologists, we keep in our book. We have two registers one if you are going to do the echo we register you, second in the Computer we put results then actually there's a 3rd one for the general clinic for the nurse to keep track. But it may not go to the details of the hospital, I don't know how often it goes because it stays in.

Interviewer: It stays in your place!

Respondent: Yes. Unless the hospital records person comes looking for them.

Interviewer: Do you have specific registers for ARF and RHD?

Respondent: Those in the study have while those who are not in the study are in the general cardiology register.

Interviewer: okay. do you have guidelines and protocols for RHD care?

Respondent: Those in the study, yes. Those not in the study, is part of the general cardiology.

Interviewer: It is the general cardiology. Okay.

Respondent: And it is like this clinician's discretion when RHD has been assumed properly, understood and mastered. So we assume that really every doctor should understand the protocols we treat very well.

Interviewer: Yeah, because sometimes they need to refer back will they be available?

Respondent: Yes. The good thing is that I have told you that at least 2 physicians have some cardiology training.

Interviewer: Okay, that's good. So for all the things I have mentioned, administration, funding, health care or workers, the numbers, medication, information flow and protocols. Let's look at the things which are working for you. You said the administration is okay!

Respondent: It okay. It is trying.

Interviewer: Okay. Funding for rhd?

Respondent: In the study yes, outside the study, no.

Interviewer: The health work force, you said you have?

Respondent: For the doctors yes, the nurses no, because we only have one nurse in the clinic.

Interviewer: No! For the medication you couldn't say much because you said you don't know.

Respondent: I don't know!

Interviewer: At least for diagnostics you have.

Respondent: We are doing fairly well.

Interviewer: Okay.

Respondent: Even though it's a bit expensive.

Interviewer: For the health information you said um?

Respondent: It is 50/50 because we gather the information but I don't know what happens to it afterwards.

Interviewer: Okay. The guidelines and protocols?

Respondent: We don't have the official protocol for those who are not in the study. For those in the study they have.

Interviewer: Okay, wonderful. So let's look at the last set of question; we are looking at your perceptions about patients out comes. Generally do think our patients are getting the care they need?

Respondent: Yes and no. Yes, because they get the diagnosis, the first part of care and get basic treatment.

Interviewer: They get basic!

Respondent: Basic treatment where I mean we give Penicillin, we give the PEN-V, the Benzathine and a few anti-failure drugs. But I want to tell you that RHD is a surgical disease; many patients who come to us with heart failure need surgery and on that we score zero because they don't get the surgery. Are you getting me?

Interviewer: Yes. I am getting you.

Respondent: Because if it's already RHD giving you heart failure, even you give them Penicillin for whichever amount, it won't get cured. They still need the surgery to repair the valve or replace it. So there we score very badly.

Interviewer: So what do you do for those patients?

Respondent: We talk to them about moving to the Heart Institute because that's where they can get the surgery. But I also know the waiting line for those who need surgery at the heart institute is very long. It is very long because surgery is expensive, the little time I was there, most times patients were waiting for camps, those who have money. And again I told you also that if your case is so advanced you are not encouraged for surgery, you are a candidate for palliation and that is very bad for RHD. But if you have heart failure from RHD, it means your RHD is already advanced and medicine will not cure you; you will take them to slow its progression or stop you from having heart failure for some time but you must get surgery to be cured but we don't have the surgery here. And let me tell you also, when you tell somebody to go to Heart Institute, Mulago- Kampala from here in Mbarara, that is a death sentence; they fear there, whether you tell them things are going to be okay, they fear.

Interviewer: What do they fear in Mulago?

Respondent: It's a new place; somebody has never been to Kampala and then the fear of money. They say "eh, to operate the heart is expensive." Then they also have some hearsay about heart surgery, maybe relatives who were operated and died. So they say, "eh when they touch your heart, you will die" Unfortunately, some cases may be true, maybe someone died after heart surgery so if somebody hears about it they misunderstand it. So there's a big fear for going for surgery.

Interviewer: Okay. So that means the communities these patients stay in also contribute to the attitude they have!

Respondent: Definitely they contribute! When you ever tell someone that "you are going for heart surgery" or they need heart surgery, huh, they are already devastated because when they go back to the community and they say "I went and saw the doctor he really diagnosed the disease that I have heart problem and I will need operation/surgery" then they will go for herbal medicine.

Interviewer: They go for herbal medicine!

Respondent: Yes because they believe that "ah, heart surgery is too much; you are going to die. I better take this herbal." They have a lot of perception then them for herbal medicine.

Interviewer: So when these patients tell their families that "I have RHD" are they encouraged? How are they . . .?

Respondent: They are shattered.

Interviewer: They are shattered!

Respondent: Me I have seen from experience; you tell somebody "your child has RHD" and you tell them what RHD is, general information, they are shattered. They start thinking that maybe they are cursed because there are not many people who get RHD how come only few get RHD. Then they start getting second opinions from very many people, unfortunately they get messed up by some people so where. So it is very bad news.

Interviewer: Do they specific local herbs they use if they don't come?

Respondent: There are some famous herbs over the radio and a lot of adverts. Some herbs are maybe what, some people say they treat everything; diabetes, hypertension, heart disease, cancer and everything. So even if someone hears that one, even if I don't mention names, it is even on the radio.

Interviewer: Because in Kampala especially in Buganda region, for sore throat there's what they call *omwetango* that's the common herb.

Respondent: Omwetango here is used for constipation.

Interviewer: They use it for constipation! Is there anything they use here for sore throat?

Respondent: They use eucalyptus leaves, you make juice. Because that eucalyptus treats flu, it is actually real, it helps with flu. So some people run to it for sore throat.

Interviewer: Okay. So doctor do you have any patients' safety concerns and quality of care . . . Of course quality of care we handled, did you see any practice and you feel that it is putting their health at risk?

Respondent: Maybe anti-coagulants; Warfarin. In the study there's ease of measuring INR, but outside the study, we are in the dark. We move in the dark.

Interviewer: You don't know?

Respondent: We move in the dark. We monitor it once a month when the patient comes back and you see there are some patients who don't tolerate this simple 5mg of Warfarin and it's the one available, the 1mgs, 2mg are in Kampala. So here we do 5mg, 10mg, 7mg and you are not going to see a patient next or another week; you will see a patient after one month or 2 months or wherever they come back. That puts them on at risk yet they need the warfarin.

Interviewer: Why is that here you have 5mg?

Respondent: It's what is on the market. You see the market forces of pharmacies, you will not stock 1mg when many clinicians only know 5mg. The 1mg and 2mg of warfarin are newer, so when you stock them they will expire.

Interviewer: Okay. So have you witnessed any preventable deaths occurring in the hospital? Surely you look at this death and you say "no, no"

Respondent: Not really. The ones I could say were preventable are these patients who get lost to follow up and then they come back when the heart failure is advanced, they have arrhythmias, they are so dilated, they have clots and you have nothing to do about it. So those are the preventable deaths but not those that have not been diagnosed because of the availability of the machine, it has done magic, tests you know what you are doing. It is very straight forward.

Interviewer: Okay. So do you think there are patients dying in the community without ever presenting to the hospital?

Respondent: Very many. I told you the problem is herbal medicine.

Interviewer: Herbal!

Respondent: Yes. It is very terrible; it keeps a lot of people at home drinking and drinking, and then they even reach a point of dying there. Then others get lost in lower health units, health center IV may not have much knowledge about it so they could diagnose these people even with TB, can you imagine! Because they have cough that doesn't go away or because they have other issues, they may not diagnose RHD.

Interviewer: So the last question, in your opinion, what are the two most important things Ministry Of Health should do to improve the outcome of our patients?

Respondent: Increase awareness through many programs, either radio or community visits or health education to know that RHD is real and at least we know we can prevent it by ABC. So let them increase the health education. It's in many ways; it is in the communities among health workers, and even in schools. Can you imagine 100 pupils in primary residing in one dormitory or even 200, because the school has 300 students? So something has to be done by the Ministry of Health and Education jointly because people get exposure from that. Then after that, we shall also need to make available the services because when you already got the disease, you need to be treated early to slow its progression. Then to cure it, it is with surgery but then let the valves be made available because valves are the ones that make heart surgery expensive. Those are the two things.

Interviewer: Okay. Thank you so much. Anything else before we finish?

Respondent: Well, I just want to thank you for this opportunity and to tell you that RHD can be eradicated too.

Interviewer: Wow. Okay, good to hear that. Thank you so much for your wonderful views. We are going to use them with a couple others to see how best we can come up with a strategy of improving the outcomes of RHD.

Respondent: Thank you.

Participant ID	HW 007 -Mbarara
Date	9 /Nov/2019

Interviewer: Okay, for record purposes, today is the 9th November, 2019, we are sitting here at Mbarara Municipal Council Health Centre IV and we are talking to participant WH007. So thank you sir for allowing to speak to us today. Just to remind you, we are looking for how we can provide better care for our RHD patients, and there are no right or wrong answers; we are just interested in your opinion. So we request you to be frank, share your opinion, your data is going to be confidential and we are not linking your identity to any information that we put in our reports. Can we go ahead?

Respondent: Yeah.

Interviewer: Thank you. So please sir, can you tell me a little bit about yourself; how old are you?

Respondent: A bit about myself or just my age?

Interviewer: Just the age.

Respondent: I am [REDACTED] years old.

Interviewer: And then what are your qualifications?

Respondent: I have [REDACTED].

Interviewer: Okay. You trained from [REDACTED] How long ago did you finish?

Respondent: I finished in [REDACTED]

Interviewer: [REDACTED]. How long have you been working? You said you working at?

Respondent: [REDACTED]

Interviewer: How long have you been there?

Respondent: [REDACTED] or?

Interviewer: [REDACTED].

Respondent: I have been working [REDACTED] years now. Previously I was in [REDACTED].

Interviewer: Okay. And then um, when you look at the patients you have seen in your practice, the demographics; first and foremost, what are the age groups you have been seeing and what are the illnesses as per age group that you notice over those years?

Respondent: For just pediatrics or in general?

Interviewer: Let's start with the pediatrics and then we look at the others.

Respondent: For pediatric patients I have been seeing, they range from about 1 month old to roughly 4 years old. Most of them are really around, below 1 year and most illnesses are pneumonia. Um, mostly

pneumonia, upper respiratory infections, cough or cold and malaria. For those above 1 year to 5 years, there's malaria and upper respiratory tract infections.

Interviewer: Then among the adults?

Respondent: The older?

Interviewer: The adults!

Respondent: It is usually upper respiratory tract infections, peptic ulcer disease, malaria, sexually transmitted diseases, um, yeah, and UTIs. Yeah.

Interviewer: Okay, thank you very much. And they um, tell me a little bit about your training on RHD. Have you been trained? Have you had any specific training in school about rheumatic heart disease?

Respondent: Yeah, we even had a lecture about it in medical school. From there, the other training was during this study for RHD campaign/ study.

Interviewer: They gave you some training?

Respondent: Yeah.

Interviewer: For how long was it?

Respondent: It was a one day workshop.

Interviewer: It was a one day workshop! Okay, and then um, where was this training?

Respondent: It was at Mbarara Target Mall.

Interviewer: Okay, thank you. And um, during your working experience, have you encountered some RHD patients? Do you see some patients as you do your work at the health Centre?

Respondent: Um, they reconfirmed cases, I saw most of them in medical school at Mbarara Regional Referral Hospital, full blown RHD patients. Then I think I saw one case of Rheumatic Fever. During my practice we have had many suspected Rheumatic Fever but I have not seen cases of confirmed rheumatic heart disease.

Interviewer: At your health Centre?

Respondent: At the health Centre, yes.

Interviewer: Okay and then um, for the suspected cases what do you do for them? For rheumatic fever because you have said you have seen some. Do you handle them at the facility or?

Respondent: Um, I usually give them, we give them STAT medicine for the joint pains, analgesics then we refer them.

Interviewer: Then you refer them!

Respondent: Yeah.

Interviewer: Okay. Where do you refer them usually?

Respondent: Usually, we refer to the main hospital.

Interviewer: Okay, and then um, so you saw only one confirmed RHD patient at your health facility where you were?

Respondent: At the facility, of course we don't have anything to confirm; we have seen many heart disease patients but we can't tell if it's RHD.

Interviewer: Okay, and then, um I am interested in what you have been taught, what is your understanding on the causes of RHD?

Respondent: Um, from my understanding RHD, it is an immune mediated disease where some antigen from Group A streptococcal group, is it group b? Group B strep, um, have antigens which are similar to some of the markers on human tissues like the heart or kidneys. So the immunity attacks those antigens thinking they are those organisms, they end up attacking the tissues including the heart in this case, which leads to destruction of the valves in this case the mitral valves, then the aortic resulting into the disease.

Interviewer: Okay, thank you. So are you aware of the link between sore throat and RHD.

Respondent: Yes, sure.

Interviewer: Okay, and then what were you told can be done to prevent RHD?

Respondent: RHD we were told once that usually in young children between 5 to 15 years, when they come with sore throat, you can treat them with Benzathine penicillin or other Penicillins and antibiotics.

Interviewer: And what were you told are the treatment options we have for RHD?

Respondent: The best and most convenient was Benzathine where you give one injection and the patients goes or you give, I don't remember, but I think Amoxicillin at a higher dose and it has to be taken for around 10 days. I don't remember that very well.

Interviewer: Okay, any other option apart from those two?

Respondent: The other option was um, the other option . . .

Interviewer: Apart from the Penicillins.

Respondent: um, I don't recall.

Interviewer: There's none, that's all you know?

Respondent: That's all I know.

Interviewer: And then, what is your understanding of the long term prognosis of RHD?

Respondent: The long term prognosis?

Interviewer: Yes.

Respondent: It depends on how early diagnosis has been made. If it has been made early, the progression can be altered so that the heart valves are not kept being hit by the immune system. Um, if it is already

um, if the valves are already been damaged, they can have heart surgery so that the valves are replaced and the survival rate can improve.

Interviewer: Okay. The first time you encountered an RHD patient was when? I mean the very last time. It was confirmed.

Respondent: Confirmed, around 2015.

Interviewer: 2015! So do you recall? Briefly tell us how you remember that patient, what did the patient present with, how old was the patient? Briefly.

Respondent: It was around ten year old female on pediatric ward at the regional referral during my, I think 5th year. The patient had difficulty in breathing, had cough, on examination it was the first case where I heard a good heart murmur of the child and I appreciated the murmuring of the heart. It was systolic murmur. Um, well, I don't remember the investigation but at least the pediatrician told us it was a confirmed case of Rheumatic Heart Disease.

Interviewer: And then um, you said 10 year old; was he in school or out of school?

Respondent: I don't know but I think she was in school.

Interviewer: Generally, do you think our patients know the difference between sore throat, ARF, and RHD?

Respondent: Our patients!

Interviewer: Yes.

Respondent: I would say no,

Interviewer: No!

Respondent: They don't know and there's need for in-depth sensitization.

Interviewer: Okay, and then um, so you have mentioned the symptoms that they describe to you. You said cough, joint pain and what?

Respondent: And joint pains.

Interviewer: Anything else they usually come presenting with?

Respondent: Um, they have a fever, joint pains and many joints. Um, well for the patients I have seen they really don't have those real symptoms.

Interviewer: Okay. And then um, are they good at follow up and adherence, in your opinion?

Respondent: The patients?

Interviewer: Yeah.

Respondent: We when well explained to and um, when we send them to the referral, they are explained to and they are told the disease themselves there they um, follow the medications.

Interviewer: But are they explained to when they are referred? Do you see that happening? Are they given enough information?

Respondent: Well Rheumatic Heart Disease being, it is one disease where you have to be . . . I mean Rheumatic Fever; because of its resemblance with other diseases, the upper respiratory infections, early malaria, it is highly missed or misdiagnosed. So even the part of health workers, they may not be in position to explain well before they themselves are able to suspect it.

Interviewer: Okay. How can we at least make them competent to really see that this one is Rheumatic Heart Disease?

Respondent: One is of course . . .

Interviewer: What needs to be done?

Respondent: What needs to be done is to have workshops with them, CMEs and tell them to increase the highly suspects; it could be one of those um, cases where patients present with fever, joint pains, sore throat and the age group, I mean that group where they should highly suspect it.

Interviewer: Okay and then um, why do you think most patients are given appointments and they don't turn up?

Respondent: Um

Interviewer: Someone has to come for an injection on a monthly basis but they come back when they are in heart failure?

Respondent: I think that goes back to, most of the patients in the whole setting are poor. So and secondly, there's poor health seeking behavior. And thirdly they tend to think that the nearest place where they get treatment is enough for them. So at first they may feel that it is unnecessary to seek for maybe highly specialized care, it is not necessary for them. They feel that where they are getting treatment is enough for them, but the other point is the poverty; they can't afford the transport to and from.

Interviewer: Okay, so those are two, some of them feel they are comfortable where they get the treatment from.

Respondent: Even from a drug shop nearby.

Interviewer: Others they don't have transport to bring them to the hospitals. Any other barrier you think?

Respondent: Still, they don't connect. In this case of rheumatic heart disease, it is something that starts small but ends in a fatal condition. They don't appreciate that casket.

Interviewer: Okay. And then let's look at the local health system barriers.

Respondent: Yes.

Interviewer: We are going to see which pieces are working for you, we are going to be mentioning different aspects and you'll give us reasons why you think it is working and why it is not working.

Respondent: Yes.

Interviewer: Okay, let's first start with administration at your facility.

Respondent: yeah.

Interviewer: Is it working for you? Does it help you do your work well as you are caring for our patients?

Respondent: The administration um, administration-wise, in this case being the administrator.

Interviewer: Yes.

Respondent: We um, we have been supporting our staff; we made sure we put in and provide the necessities within our capacities especially financially. We put on refresher CMEs to keep the health workers competent.

Interviewer: Have you had any CMEs targeting Rheumatic Heart Disease? Have you had any?

Respondent: Yes, it was delivered by this team.

Interviewer: Oh, when they came to your place!

Respondent: Yes.

Interviewer: Okay, and then um, what else are you doing for your teams so that you make their work easy as an administrator?

Respondent: We keep them highly motivated.

Interviewer: Um, in what way? How do you keep them motivated?

Respondent: There are small allowances for extra activities usually outside the facility. Inside the facility, we make sure we usually extend small amenities like water and electricity to their residential places.

Interviewer: Okay, now let's look at the leadership in the district, is it helping you anywhere? Is it helping you do your work in your facility?

Respondent: Yeah the leadership is definitely helping. They help recruit more staff members and it has helped renovate some buildings and building some facilities. I think it is working.

Interviewer: Do you get any supervision from them?

Respondent: There's a constant or regular supervision from the District Health Officer and even the other officials from the district.

Interviewer: So you feel that this this working for you and you don't have issues!

Respondent: Yeah.

Interviewer: Let's go to the funding for health care in general.

Respondent: For health care in general!

Interviewer: Yeah, is that working for you?

Respondent: Funding is 2 ways; the consumables at the facility's, running, maintenance of the facility, and then the drugs. Funding has never been enough or near enough but at least it's there to keep basic things like water and electricity. The drugs last for some while then stock outs. So there's still much more needed.

Interviewer: So usually for RHD patients who cannot come on monthly basis for Benzathine they are referred to health facilities near their places.

Respondent: Yes.

Interviewer: So if um, an RHD patient came to your facility would they at least find the medication there?

Respondent: In this case Benzathine!

Interviewer: Yes.

Respondent: It would be there. It is there.

Interviewer: It is there! Have you had stock outs?

Respondent: Currently for Benzathine? No

Interviewer: Do you receive any RHD patients who come to your facility?

Respondent: um, I wouldn't be in position. Maybe they come when I am not aware.

Interviewer: You don't get to know about it!

Respondent: I haven't been told one.

Interviewer: Okay, um, so from what you have said it looks like there's no any funding specific for RHD at your facility!

Respondent: Umm, not currently.

Interviewer: Okay. So now let's look at the health worker staffing and qualifications; how are they at your facility?

Respondent: Currently at the level of Health Center IV, our staffing I can say is good.

Interviewer: It is good! You have enough staff to handle the . . .

Respondent: Per cadre we have enough staff

Interviewer: Well qualified for their work?

Respondent: Yeah, we have 2 medical officers um, 3 three clinical officers and other clinical officers in the specialties, about 11 nurses, 10 midwives. At a level of a Health Centre IV, the staffing is okay and they are competent at that level.

Interviewer: How about the waiting time for our patients, if you look at it what do you have to say about it?

Respondent: The waiting time is still um, we serve a large population the facility being in a bit of a town. We serve more patients than from our attachment areas. So still waiting time is still a problem. They are many.

Interviewer: Okay, how about the quality of care that is given to the patients in the facility?

Respondent: [laughs] there's always a room for improvement, I can say that. But currently, we give the best.

Interviewer: Okay. What is lacking? What would you have done better to make it perfect?

Respondent: Um, in terms of quality of care?

Interviewer: Yes, for the patients.

Respondent: Okay, if I wanted to improve I would strengthen quality improvement committees to ensure maybe monthly meetings to ensure quality projects to improve areas that are having quality issues with a focal person for that quality improvement. I would ensure regular CMEs that are funded with needed materials, um, then also have staff workshops or tours to centers of excellence in the region to see how better they can improve themselves.

Interviewer: Okay. So you talked about getting training from these guys, who else was trained apart from you?

Respondent: Um, and the rest of health facility workers were trained from the facility.

Interviewer: They were trained! Okay, are you comfortable saying that probably now they can identify a case, if it came to the facility after the RHD training?

Respondent: Yeah, most of them but there is need for a refresher.

Interviewer: Okay, and then um, let's look at the medication; you said Benzathine, you have it in stock!

Respondent: Yeah.

Interviewer: Do you have any heart failure drugs that you have in stock at your facility?

Respondent: Um, heart failure! I think at the level of a Health Centre IV, some of the drugs we have may be for heart failure but they are meant for other conditions like hypertensions. So we are not supposed to be seeing heart patients.

Interviewer: Okay, you are not supposed to handle them. And um, so even the diagnostics don't have!

Respondent: We don't have.

Interviewer: Okay, let's go to the health information and your medical records system, what do you have to say about it? Is it working for you?

Respondent: The medical records system!

Interviewer: Yes.

Respondent: The medical records system is a bit of a challenge. It is hard using hard paper because sometimes we run out of stock of stationery and space to keep the records. So we would wish to go electronic if we could manage.

Interviewer: So could you say when you at your staff, if you went digital would it be easy to take on the medical record?

Respondent: Yeah, most of the staff are computer literate, so they just need a refresher for specific programs.

Interviewer: Okay. Do you have any registers for . . . you said don't handle those patients because . . . ? Because I was going to ask you if you have any specific registers for have ARF and RHD but you don't handle that. That's what you said.

Respondent: Yes.

Interviewer: And that means you don't even have any guidelines and protocols for RHD?

Respondent: Yes.

Interviewer: But do you have a clear way of referring such cases in case they came to your Health Centre?

Respondent: Usually we have referral forms.

Interviewer: You have!

Respondent: We usually have but sometimes when they run out of stock, we just write in their books and, because there's only one referral, we send the patients there. It's the only step next.

Interviewer: So um, from the list that we have gone through, we are just going to see what's working for you and what's not working for you. Administration, that one you said that is okay.

Respondent: Yes.

Interviewer: Funding for health care; you said it's never been enough.

Respondent: Yeah.

Interviewer: It is lacking. Health worker force, you said you are okay with it. Medication of courses specific on RHD management, you said you don't handle.

Respondent: Yeah.

Interviewer: So you don't get those drugs.

Respondent: We don't.

Interviewer: But you have BPG.

Respondent: Benzathine! Yes we have.

Interviewer: Okay.

Respondent: Though we don't know if you sent us many patients we'd still be having enough.

Interviewer: Oh, you do not know if you would have enough.

Respondent: It is shared by other patients like those with STIs, syphilis.

Interviewer: Then for the health information, you'd advocate for digital!

Respondent: Yeah, digital system right from the patients up to the Centre for the collection of data.

Interviewer: And the guidelines and protocols? Do you think if you would need them at your facility for RHD care?

Respondent: Acute Fever, yeah the guidelines are okay for the acute rheumatic fever but then for the heart . . .

Interviewer: RHD

Respondent: [laughs] for RHD? Really no.

Interviewer: You don't! Okay, so for the last part of the interview, let's look at your perceptions of patient outcomes. Do you think the patients are getting the care they need?

Respondent: Um, being that most of the diseases like it has been always been said, we are still at a level where we are mostly hit by infections and other diseases that can easily be prevented. And, health Centre IV like any other health center centers on prevention; they deal much in prevention. And in our work plan, we focus much on prevention of diseases, so I believe we are giving above um, moderate.

Interviewer: Moderate!

Respondent: Yes.

Interviewer: Okay. So at least for sore throat am sure if they brought a kid with sore throat, you can handle.

Respondent: Yeah.

Interviewer: So um, do you think these parents, the parents to those kids are given enough information about the dangers and the more serious implications of having this sore throat recurring? Do you think they get that kind information at the facility when they come?

Respondent: Um,

Interviewer: So as prevent the bad cases of RHD?

Respondent: Many health workers are now informed about it and the need to suspect it about the ARF and RHD. But then like we said earlier, the lines, the waiting time, the patient numbers, we don't have a good time for a health worker-clients to explain more. So I would advocate, maybe I would even implement it if possible that we give health talks to our patients at the facility and once in a while in the communities. Then it would be easier to reach out to many people at once.

Interviewer: Okay, that's wonderful. Surgeries; you already said that you refer the cases so that wouldn't apply to you. Do you have any patient safety and concerns at your facility?

Respondent: Patient safety.

Interviewer: Yeah, you know there are practices where you see that surely you are putting the patient's life at risk or where you could have done better.

Respondent: Yeah, like any other place, we always have that place where you see we could have improved where you can see there was as a mistake on the part of the health worker. These always happen.

Interviewer: Like which scenario can you give? Like what incident?

Respondent: Sometimes antibiotics are given to the wrong conditions and some diseases are diagnosed when maybe an investigation could have been necessary to confirm.

Interviewer: Okay. Are you seeing any preventable deaths in your facility?

Respondent: preventable deaths!

Interviewer: Yeah, someone goes but deep inside you know honestly this wouldn't have happened.

Respondent: Yeah sometimes I have seen deaths where maybe we delayed to do something, to put an intervention partly because of stock outs or partly because the health worker did not highly suspect the condition.

Interviewer: What could be the stock out? In what area?

Respondent: Stock outs, for example, we have had stock outs on what you have talked about, and for example we have had stock outs in TB diagnostics. So you have a suspect but you don't have a test immediately.

Interviewer: Okay. Do you think our patients are dying in the community without presenting to the hospital?

Interviewer: Yeah, sure a lot of them. Some relate it to witchcraft; they're at home praying, visiting traditional healers, while others don't have money to take them to facilities. Others simply, I don't know how to call it but there's that negligence even to the extent of being negligent to yourself not to seek care.

Interviewer: Okay. Any other, anything else that is keeping them from coming apart from the ones you have mentioned?

Respondent: Um, maybe some feel that the facilities may not help, that they may not be in position to help.

Interviewer: Why would they feel that? Why do you think they have that kind of . . . ?

Respondent: Because there has been a period where probably health facilities were not functioning well to the extent that some people even lose lives in the health facilities. So some don't believe that there has been an improvement.

Interviewer: Um, as we finish, I have two more questions. One; what are the two most important things you think MOH, Ministry of Health should do to improve patient outcomes?

Respondent: One is to increase staffing of health workers.

Interviewer: Which cadre mainly?

Respondent: Cadres! For example, at the level of Health center IV, staffing fully with 2 medical officers and senior nursing officers. Then the other one is to improve, to provide a bigger budget for drugs and also improve on the supervision of those drugs.

Interviewer: Okay, one last question, is there an impact . . . If there is probably um, let's look at the RHD patients, If he tells the community "you know what? I went to the facility and they told me I have this disease," are they helped in the community?

Respondent: If? Come again!

Interviewer: If a patient or someone who has RHD goes to the community and tells them, "you know what, I have been diagnosed with RHD." Does the community help our patients in any way? Do you think they are helped?

Respondent: The community, I don't know but maybe depending on the social status of that community and such a condition having less stigma for example related to HIV, they are usually helped; funded to meet the costs and even more psychological support. If the community is able to . . . especially in terms of finance if the community is able to and if it's not, still they will give more psychological support.

Interviewer: Is there stigma associated with it RHD?

Respondent: No.

Interviewer: It's not!

Respondent: It's not.

Interviewer: Okay. Anything else you want to add before we finish?

Respondent: Um, maybe um, I have been following this study from my colleague. Much as I knew RHD commonly in children, I did not think it is to that extent as revealed by the research. So I would feel that it starts as a condition from a level of health centers and not at higher institutions. So you should put more focus, the ministry should put more focus to make sure the health workers and the health system at that level is able to pick those patients to prevent the full grown condition of RHD which is more expensive to manage. This can be in a way that more training is funded in the area and drugs for prevention such as Benzathine are more stocked in more facilities at the level of health center IIs, IIIs, IVs and also improve on the staffing the cadres especially clinical officers and medical officers who may be able to diagnose these conditions. Then they can put guidelines for quickly picking up of this condition like they have done for TB and other conditions.

Interviewer: Okay. Thank you so much for that information. We shall use that information and the information we have gotten from other participants and come up with strategies of improving our care for the RHD patients.

Participant ID	HW 008 -Mbarara
Date	12 /Nov/2019

Interviewer: So today is the 12th of November 2019 and we are at Mbarara Regional Referral hospital, meeting one of the health workers. Morning sister.

Respondent: morning.

Interviewer: Thank you for giving us this time.

Respondent: You are welcome.

Interviewer: Um, this is participant ID WH008. So as I had told you, this study is to determine how to provide better care for RHD and there are right or wrong answers. Express yourself and we ask you to be frank and share your opinions. The data we gather here is totally confidential and we won't link your identity in any of your comments in the reports that we produce.

Respondent: Okay.

Interviewer: So please tell me about yourself; your age. How old are you?

Respondent: I am a nurse working at Mbarara Regional Referral hospital. I have worked here since [REDACTED] up to today.

Interviewer: Okay, tell me your age; how old are you?

Respondent: I am [REDACTED] years old.

Interviewer: Okay, and you said you are a nurse?

Respondent: Yes.

Interviewer: Where did you train from?

Respondent: [REDACTED]

Interviewer: Okay, which year did you finish?

Respondent: In finished in [REDACTED].

Interviewer: [REDACTED], so how long have you been in practice?

Respondent: Its now [REDACTED] years.

Interviewer: Wow, and how long have you been working here at regional referral hospital?

Respondent: [REDACTED] years now.

Interviewer: [REDACTED] years now! Okay.

Respondent: [REDACTED]

Interviewer: Okay. So the patients you see at this hospital, tell me about them; how old are they? Which age groups?

Respondent: Age groups, in fact those with RHD . . .

Interviewer: Generally.

Respondent: Generally, mostly 6 to any age.

Interviewer: Okay, and are they mostly female or male?

Respondent: Mostly females.

Interviewer: And what are the common illnesses do you see in each of the age groups?

Respondent: The young ones usually present with fevers, loss of weight, sore throat and cough which is not productive, then they get . . . Usually by the time they come here, they come when they have these complications of swelling of the stomach and swelling of the legs.

Interviewer: Okay. Here you are talking specifically about RHD?

Respondent: Yes.

Interviewer: How about other illnesses?

Respondent: Mostly we have malaria, typhoid, Brucella and we have HIV patients but usually they come when they don't know what they are suffering from and then the diagnosis is made after they have come.

Interviewer: So tell me, are these people inpatients or outpatients? What are the common diseases you see in inpatients and outpatients?

Respondent: With these outpatients, it's always these flu, cough, fevers and even accidents for those who get them every second. Then these of malaria are diagnosed sometimes and they come with these symptoms like fevers and headaches. They come in after checking their blood. If it's RHD, they usually come with fever, coughs, and chest complications and so on. But the inpatients who usually come with severe anemia are usually admitted. Those with complicated malaria which has been treated for so long and is not healing and they need further investigations. Then there's this typhoid; usually those with typhoid come when they have complications and are admitted. Diabetes complications are also admitted and those with RHD are of course admitted when they come even before they are diagnosed because they come with other complications at times, they are admitted and removed from complications.

Interviewer: Any other illnesses?

Respondent: Yes. There are these TB Patients and it is rampant these days because it comes as a complication of those people who don't take their ARVs steadily, then they leave care. So the TB is now very common.

Interviewer: Okay.

Respondent: Although we don't admit most of them, we have them as outpatients and they are many.

Interviewer: Okay. Now tell me a little bit about your training in RHD; did you receive any training during school about RHD?

Respondent: No, they just talked of it as the liver. But then I just got training when I joined this study.

Interviewer: Okay. That was after your graduation?

Respondent: Yeah.

Interviewer: So, when was that training?

Respondent: It was 2013.

Interviewer: Where did it take place?

Respondent: It was in Seeta, Mukono.

Interviewer: By who?

Respondent: By doctor, he said he was doctor . . . um, I am forgetting the name of the doctor.

Interviewer: Do you remember how qualified he was?

Respondent: Um, yes. They were three doctors from URHD and there was Doctor, and then Doctor

Interviewer: You said that is 2013?

Respondent: Yes.

Interviewer: Okay. So now, how many patients of RHD do you see per day?

Respondent: Per day I can see about 2 and monthly we usually have a general clinic. We usually share the number of those patients into two so that some are seen this month and others the next month. And on a clinic day, I see about 35 to 40 patients.

Interviewer: That's per month?

Respondent: Yes.

Interviewer: So that means per month you see 36 to 40 patients.

Respondent: Yes.

Interviewer: Okay. Are these inpatients or?

Respondent: Outpatients.

Interviewer: Okay, now I am interested in what you were taught during that training of RHD. So what do you understand about RHD?

Respondent: RHD is a condition where someone's heart valves don't work well; they are usually swollen and they are caused by a virus which causes sore throats and influenza which are not well treated. These bacterial diseases which are not well treated lead to the valves of the heart, the valves swell and you find

that the opening is not okay, blood does not move freely to the chambers and that's when you find water on top.

Interviewer: Okay, what do you have left there? Anything you can tell us about RHD?

Respondent: Um

Interviewer: The cause. We are on the cause now.

Respondent: The cause is usually a bacteria.

Interviewer: Do you know that bacteria?

Respondent: I don't know, it is . . .

Interviewer: So are you aware of a link between sore throat and RHD?

Respondent: A link?

Interviewer: Yes, are those 2 related?

Respondent: Yes.

Interviewer: How? How do you relate them?

Respondent: Like I said when someone gets a sore throat caused by bacteria and it is not well-treated, the bacteria remain there and cause some clots which come and make the valves sink in. when they sink in and don't close, they really make someone's breathing sort of cut off, then someone will start to talk of palpitations, tiredness, not feeling okay and not being able to move uphill.

Interviewer: Okay. What were you taught can be done to prevent RHD?

Respondent: What we were taught is to usually make sure we advocate that whoever gets a sore throat should go to a medical personnel or hospital and be treated thoroughly, and finish the treatment. The on and off fevers have to be treated with a full dose so that you don't leave some of the organisms untreated. We should make sure that when a child complains of sore throat, don't just go to someone and say "give me Penicillin so that I go and treat;" you have to take that person to a medical personnel or doctor so that they check and see. We are always telling them that when this child has a problem of breathing, don't just treat it in the village or go to herbalists to give some herbs. No, you bring the child to hospital and whenever they tell you "go do these investigations" do it and go back to the doctor so that the child is treated well. And for the grownups, we always tell them "when you are feeling pain in swallowing, palpitations, you have problems when sleeping at night or fail to sleep without putting pillows, go to a medical personnel; go to the hospital. Go and they do an ECG ECHO to see if your heart is really okay.

Interviewer: Okay.

Respondent: and usually when you go to a health center, you have to inform them whatever you feel and when they give you treatment and not respond, you go back and tell them so that they can treat it very well. And whenever you get treatment and you feel you have not cleared, don't just keep quiet and say "it will go."

Interviewer: Okay. So, any other? Any ways you were taught can prevent RHD?

Respondent: Yes, we have to teach people where to go when they have problems, and maybe if someone has approached you with such a problem, you have to make sure that person is treated. He has to come back for checkups because if one goes and doesn't get back, it means he is a lost case. RHD doesn't go like that and in most cases it doesn't cure; the patient has to remain in treatment. Usually we have to explain that. When a patient is found with RHD, we tell them "with this condition, you will be okay and live with it and do whatever you want to do, and there's also a chance of being operated, when you have money. When you are on drugs you won't have any complications" so that these patients know their condition and that they are supposed to stay on treatment, because some of them when they feel that they are okay, they leave the treatment and disappear. The first thing we do is tell them "please, this condition doesn't go like that; you have to keep coming back. You have to come for you revise. Maybe this condition can be operated and then you will be okay, but still you will be on drugs until the physicians or doctors tell you to stop.

Interviewer: So now am interested in what you were taught are the treatment options for RHD.

Respondent: The treatment options; usually we tell them that get an injection every month for at least the rest of your life. If you are not to be operated or if it is to be stopped, there are some...

Interviewer: Which injection is this?

Respondent: Benzathine.

Interviewer: Okay.

Respondent: And we tell them that if we are to stop the treatment, that will be the doctors' options. But there are some who can't get the injections. There are some who react on penicillin, those can use erythromycin and there are some who can't even use the injection. So they can use penicillin injection for 5 days. We give penicillin and erythromycin and others that I have not mentioned.

Interviewer: Any other treatment options for RHD? Besides antibiotics?

Respondent: They are operated and they put in a new valve.

Interviewer: So what's your understanding of the long term prognosis of RHD? What is the prognosis of those patients?

Respondent: Usually the prognosis is not all that good because some of them fail to take the treatment the way they are supposed to treat. Some of them come when they already have complications and they are taking a lot of tablets plus that injection. So you find a patient having a lot of drugs and it is somehow difficult to take, so that patient stops taking. So you find that in 2 – 3 months the patients are okay and responding but find that after a few months, they start to deteriorate and when you ask, some of them tell you "I don't have money to buy those drugs" the captopril, Lasix . . . so they get other complications. You also find drugs are many and expensive, so the patient can't buy them. He says "I take them, when they are over, I wait." Like now we have some injectors, they give them some drugs but at times don't have them that makes them get poor prognosis because of irregular taking of their drugs.

Interviewer: So now you are going to tell me about your encounters with these patients; do you remember that last RHD patients you worked on? The very last one?

Respondent: The last one we registered or saw?

Interviewer: Any; it can be any. I don't want their names, but I want you to recall their age, sex . . . give me a brief summary of this person, how did they present?

Respondent: Okay. At first when he came, he was weak. He used to cough, get fevers and couldn't move uphill. After getting treatment, he improved but that was after like 2 years. He gained weight and started working. Then there in the middle, I don't what happened, but he told me that he had gone to the village so he couldn't access the drugs, so he spent like 3 weeks without the drugs. When he came he had deteriorated, so I asked what happened and he said and told us "I was in the village and I couldn't buy the drug; I had the money but couldn't get the exact drugs." So he came, got his drugs and became okay. Infant last Friday he was here; he is on his drugs and he can tell you that he can do anything. He can do his work and dig; he has no problem although he is waiting for surgery.

Interviewer: Is that the latest patient you saw?

Respondent: Yes.

Interviewer: That's the 26th of last month?

Respondent: Yes. In fact this month I have not seen any.

Interviewer: How old was he?

Respondent: 43 years.

Interviewer: Is he working or not?

Respondent: He is self-employed.

Interviewer: okay. So these patients that you see, are they aware of the link between ARF, RHD and sore throat?

Respondent: Some are, but some are not, because at times, I told you some patient's regularly tell you, "I didn't have transport so I didn't come" Usually the doctor tries to tell them that . . . he gives them a lecture before. At least he tries every month to tell them, "if you have someone who is like this at home bring him because it can be RHD" Some pick and some don't pick. Because you at times ask someone "have you ever had someone with this and that?" and he says "yes." And you ask "why didn't you tell us and he says "me I didn't even know that."

Interviewer: So what sort of symptoms do they present with?

Respondent: They usually present with swelling of the body; they tell you they become tired as they walk, they lose appetite and you see someone looking small or under age.

Interviewer: And generally, do these patients come for follow up?

Respondent: Yes.

Interviewer: Do they adhere to the drugs? Tell us about the follow up chain and adherence to the drugs.

Respondent: These patients come these patients usually start when they are weak. When they are on their drugs, they come back. You find someone telling you "this time I have no problem; I can do all sorts of work, and I am at school studying. I can get what they are teaching, so I have no problem." When

someone has taken the drugs the way they are supposed to be taking it, they come back so that they check the heart and sometimes get drugs. When we have (drugs), they get and when we don't have, they go and buy. But some of those who don't have money, it's a problem. You find that the adherence is poor. The drugs are here but when they get drugs and come back for review, they come back when he is okay. Then after they get the drugs, you find that there's no food; she eats whatever she wants. So you find the patient deteriorating. In fact we have that group of the poor; their adherence is poor due to financial problems and drugs because even at times they fail to come for drugs or even buy drugs. We can also provide the drugs but we don't have all of them. So at least those that have some money for up keep are at least okay.

Interviewer: So you have told me about the patients that don't come back. Now I am interested in what they tell you are the reasons they don't come back.

Respondent: The reasons are usually "we don't have money for transport" and when they stay home, "we had no drugs so I was just there on God's mercy."

Interviewer: So personally, what do you think are the reasons? These are the ones they tell you, but as you, what do you think are the reasons why they don't come back for follow up?

Respondent: Some of them are genuine reasons; they don't have money. Some of them are just stubborn; they feel that maybe this one has been bewitched. They be like, "we should go to a witch doctor" because the patients can't stay on the drugs throughout. Then outside you hear them telling stories, like, "You know there is this child who had a disease like this and they went to a witch doctor who cured that person." But then you also hear another person saying "no, even if you go there. Me I have moved all around and I have not been cured, that's why I came here." So with such people you find that they are taking drugs and also going the other side and by the time she feels like, "ah, let me go for herbs!" that person goes and disappears and sometimes they come when they are not in good state, and then they tell you "I had no money to come" or "I had no money to buy drugs" but you know he is deceiving you. But there are people who say, "I don't have money" and you see that really they don't have money!

Interviewer: Okay.

Respondent: There was a certain woman who had failed to come now she has picked up, now she comes back and she's okay.

Interviewer: So we are going to talk about health system barriers, you will tell me which pieces are working for you and which ones are not and you tell me why. So let's look at the administration here at the hospital and at the district, does it work for you?

Respondent: No. They don't help us because when they bring the Benzathine, they give it to us with the syringes and water for injection. But the other drugs like Lasix, lauzatone, Spirilactone, we usually don't get. They tell the patients to go to the window and when they go there, you see our patients are weak. There's a queue which is for sometimes an hour. So they give up and when its lunch time, they close and go. So you find the patient saying "I failed to get the drugs, I can't go back (to the hospital)." You find that the administration helps us when the drugs are there but when they are not there, in regards to RHD patients, there's step that is taken.

Interviewer: So how about the funding for health care in general, is it working for you?

Respondent: No. Which funding is that?

Interviewer: In terms of money for buying drugs, supplies, everything that you use generally at the hospital.

Respondent: That one I don't know.

Interviewer: How about for RHD, does it work for you?

Respondent: No. They have never funded us; it's the other studies that used to fund.

Interviewer: And how about the health care workers, in terms of numbers and qualifications, is that working for you?

Respondent: No. in general or for the RHD?

Interviewer: Yes.

Respondent: I am there with Doctor

Interviewer: Are the numbers working for you?

Respondent: No, I wish we are having someone else, but the study said it will get. As per now we are just volunteering for those patients we had and we are registering new ones. We said, "Let's work for this year, maybe when we fail to get something that can keep the patients, then we close and they go to the general cardiac clinic."

Interviewer: So in the general cardiac clinic, are the numbers working for you?

Respondent: I am not aware.

Interviewer: How about the waiting time for these patients, how is it?

Respondent: The waiting time is also a bit prolonged because I am alone taking vitals and everything, then sending to the doctor. The doctor is one of course. If they are forty, we take a day.

Interviewer: How long do you think it takes a patient from the time they arrive to the time they meet the doctor?

Respondent: More than 2 hours.

Interviewer: How about the quality of care the patients receive, is it working for you?

Respondent: Not really because that's what I would be expecting or they would be expecting from us. I would expect that when they come, they are given treatment and they go, because they are weak patients. But when they come, they have to wait; I have to take the vitals, they have to see that doctor and at times if we have some drugs, they have to wait and then I would give them the drugs when we are finished. Because you can't say am weighing this one, am giving this one medicine, am measuring pressure then giving drugs too, you find it confuses everything.

Interviewer: Okay. And how about the medication; BPG, anti- coagulants and anti-failure drugs. Are they working for you? Are they enough?

Respondent: No, they are not enough. As per now, we just give the patients the . . . but for all the patients, I give Benzathine and the others they but for themselves or the get at the pharmacy.

Interviewer: How about the diagnostics; the ECHO cardiography, what do you say about it?

Respondent: At times it's working and at times it is not working.

Interviewer: What do you mean?

Respondent: That would be okay but you find the machine is working today and tomorrow it is not working. If a patient had an appointment to do an ECHO, it is not done. When you give him another day, the patient comes back and the machine is not working. You find that it takes 6 months without doing that ECHO. Like the other time, the ECHO took like 4 months when it is not working.

Interviewer: Do these patient get this service for free?

Respondent: Yes, when it is working. When it is okay, they get treatment.

Interviewer: How about the health information system; the medical records For RHD patients are they working for you?

Respondent: Actually, it has been working because we record them. We give them appointments and they are recorded. Those who are nice patients, they come and they go back. It is recorded; I don't think I have any problem with it.

Interviewer: Is there a link between the registers you have here for RHD, outpatient and in patients?

Respondent: No, because I have never seen them come here for these registers to see if they can compare so they can admit. But usually they have their Rheumatic Heart Disease numbers and when they admit them, they write the number down. I think that's the link because they use that number.

Interviewer: For example, if you had a patient here and was admitted. If that patient came back after 4 years and you wanted to look for that patient's records, can you get them?

Respondent: Yes, on the ward.

Interviewer: How easy is it?

Respondent: It is not easy, but you have to dig out and get it because it is in the register and the number is there. Here you have a date when the number was written and when you go down, you check the day the patients was admitted.

Interviewer: Do you have registers for Acute Rheumatic Fever?

Respondent: No.

Interviewer: You don't have specific register?

Respondent: No.

Interviewer: How about the guidelines and protocols for Rheumatic Heart Disease and care? Are they working for you? Do you have any?

Respondent: We have them.

Interviewer: How about the referral path way for these patients, what do you say about it? The referral RHD patients.

Respondent: From outside to here?

Interviewer: Yes. How do they get into the system?

Respondent: The ones we have got are from Mulago Hospital; they are just making them get services from a place nearer to their homes, and these days we are getting them from Nyamitanga or Innocent (medical center) but in the hospital setting, I think it is from Kabale hospital. I think we have got about two patients referred here. But in other hospitals, they usually send them to be diagnosed; they don't say it is RHD. They say "go confirm if it is RHD. Go for confirmation and proper treatment."

Interviewer: So we are going to go through these pieces. You said administration don't work for you?

Respondent: It is fair.

Interviewer: And the funding for health care and RHD specifically? Is it working?

Respondent: It is not.

Interviewer: It's not working also. And the health care worker numbers and qualifications, are they working for you?

Respondent: Not really.

Interviewer: And the medication; BPG, anti-coagulation drugs, heart failure drugs and injections. Is it working for you?

Respondent: It could be working for the patients and at first, it were all the patients, but now since the other study is over, now we are just there. We give some of the drugs and some we don't have. I think it is not working.

Interviewer: Okay.

Respondent: Because if give some drugs and not give other drugs, it is not working.

Interviewer: Okay. And the medical records system is working for you?

Respondent: It is working.

Interviewer: Okay. The guidelines and protocols for RHD care?

Respondent: No.

Interviewer: Do you think it is good to have them? Do you need them?

Respondent: Yes.

Interviewer: So now, the last set of questions, here we are going to look at the perception of patient outcomes. Generally, do you think these patients get the care they need and why?

Respondent: They get not exactly what they need but they get some here. Why I am saying that is that when you write treatment, and maybe take the vitals and give the Benzathine but you have not given other drugs and you have not even monitored, how is that patient going to take those drugs? You can't say it is good because these are outpatients. I usually give the Benzathine myself but these treatments, the other drugs, you don't know if the patient took them. Usually you give them the right dose but the patient may mess up and take it another way because they don't take time here that you will monitor and see how they are supposed to take. You would monitor how they take the drugs for 3 to 4 days and when you are observing, you'll know that they are taking it the right way. They come, we treat and they go away; they at times can buy a drug of 50mg when they were given 25mg and they don't tell them "take half" so you find that the patient took it all.

Interviewer: So you think you are not actually . . .

Respondent: Yes.

Interviewer: How about the surgeries; do these patients get surgeries?

Respondent: Yes, we have some who have go it and some are promising to go.

Interviewer: How easy is it?

Respondent: It is not easy because the patients have to pay. And you know when it comes to money that is a problem. They usually contribute for their tickets and other things; we put in something. It is not that easy.

Interviewer: Where are these operations done?

Respondent: In Sudan, now it is done in Mulago because we have one who was operated from there and she is okay. She has just delivered.

Interviewer: That's great. Do you have any patient safety concerns? For example, preventable deaths in the hospital where you look at the patient and you say "for sure this person wouldn't have died"

Respondent: Yes.

Interviewer: What was the problem?

Respondent: It was a young patient, 15 years old; she was admitted through emergency and from there, they took her to the cardiology ward. That patient was there for 3 and half weeks but would miss treatment; it was not given at the right time. There are times when she couldn't get treatment because the treatment was over and she didn't have money to buy, and it was just Lasix. They couldn't buy because the aunt had spent all the money. When you are admitted here, you have to eat and drink. They were from Ntungamo and they had to buy drugs, so you find things are not easy. That child would have survived if maybe we could help buy some drugs and maybe facilitate the aunt to eat and drink, maybe she would been there. However, there was a time she reached a point and she said "I am taking this girl" and I said "don't leave." Now she was asking me, "what if she dies here, what would I do? How will I take the body?" So I said, "God will provide" but God can't come from heaven and provide, so that girl was there. After something like 13 days, she died and she had stayed for like 4 days without treatment. There was also this other woman; she didn't have money, was on treatment for 3 days and then the treatment got over. She couldn't buy the drugs and had nothing to eat. The attendant who came after 3 days was an old

woman of about 80 years; we could ask her for this and that but she would say, "I don't have money." They stayed in the medical ward, they contributed for some time for about 3, 4 days, but that woman had to die. When they are not there, the drugs are expensive but those drugs . . .

Interviewer: Those drugs are not provided by the hospital?

Respondent: They are not enough. That's why I told you that from 3 days, you find a patient couldn't get drugs when they get finished. At times they give a certain amount at the ward and when they are over before their time is due, they (care providers) say, "we gave you drugs for this period!" but they (patients) will say, "Now where can we get more?"

Interviewer: Do you think there are patients dying without presenting to the hospital for care?

Respondent: Yes, they are there. Because when you go deep in the village, they have patients, and they will tell you, "we have no money to take the patient to the hospital and even if we take the patient, he needs an attendant and yet both the patient and the attendant have to eat and drink. When you go the hospital, they tell you to go for an x-ray but you don't have money, or they tell you to go for blood tests and you don't have money." Everything needs money. So they end up leaving the patient; they say, "How can we take this patient?" They end up leaving the patient to die, and this is not just for RHD but also for other diseases.

Interviewer: Is there another thing that stops them from coming to the hospital for care apart from money?

Respondent: Some people are careless; you will see someone with money but they fail to facilitate someone to go to school. Some are careless; some mothers say, "I am going to the garden, now imagine carrying this child to the hospital! Besides, she is a big woman. Let me go and cultivate for my kids."

Interviewer: So as we are concluding, what are the two most important things Ministry of Health should put in place to improve the outcome of our patients?

Respondent: Ministry of Health should at least recruit more medical personnel in different departments so that the services can go neat, because now everywhere you go, there's a shortage. You find one nurse with 50 patients! Can that nurse perform or give quality service? Then underpaying medical personnel demoralizes us; you feel like "ah, even if I work the whole day or week, what am I going to gain? At the end of the day I am not going to pay my child's school fees." So when you work when you are not motivated you feel like "let me work for some time" and at times you just work to be on duty and not actually offering services. Then the other thing is to at least provide drugs in hospitals, enough drugs especially the ones that are expensive. They bring the cheap ones! And for the expensive drugs, the patients are told to buy. The Hyperstensives and these diabetic patients are in trouble; they care for themselves. People can't afford but at least I wish they can increase the amount of drugs according to the needs of the patients. Because at least here it is referral, we have many patients but you find that they bring drugs that can last for 2 months and yet they are supposed to be 3 months! They usually bring at 3 months yet the drugs get done at one and half or two months, so the remaining one and a half months you find patients have to buy for themselves. Even if you are a nurse, doctor or medical personnel who wants to offer services, you also wonder how you go and tell an old woman of 80 years, "You go and buy your drugs!" First of all these patients don't know those drugs; they just go to the pharmacy and they give any drug and they have that thing of saying the wrong drugs to the patients. They say, "It will work as this"

because this one is cheap and the other is expensive. So a patient brings drugs you didn't send them for and they tell you, "They told me it works like the other one because I had no money to buy the other one." So to me, they bring drugs which are enough. Maybe the nurses and doctors can get paid but when the drugs are there, they will give the best services.

Interviewer: Thank you so much. Do you have any other thing you want to add before we close? Because we have finished?

Respondent: If at least the government could sensitize these people about diseases at least in a massive way in the village and not in towns or hospitals, but in villages where these patients need help. Because if they are to sensitize, someone will listen in their language and at least get to be like, "Oh, I have a child or mother who has these signs and symptoms." Then they will bring him and we see. But usually, things are done here in the hospital or towns, so you find when you go Kinoni town or a health center II, you find some 30 – 40 people but in the villages like at the parish level, that is where you meet these patients. Some of these people don't even have radios, so you find that they can't even hear our advertisement "come to Mbarara Hospital in the white tent . . ."

Interviewer: Okay thank you so much for your time.

Participant ID	HW009
Age	█
Date	15,November, 2019
Venue	Mbarara regional referral hospital
Interviewer	

Okay, we are in cardiology room at Mbarara regional referral hospital, nice to meet you Doctor, you are welcome and thanks for giving us your time, so this study is to determine how to provide better care for RHD, that is for rheumatic heart disease, and there are no right or wrong answers, please frank and share your opinion, the data we gather here is confidential and we shall not link it to your identity or to any of your comments, to any reports we produce, so tell me about yourself doctor, how old are you?

Respondent: I am █ years old

Interviewer: okay, what are your qualifications and where did you train

Respondent: I trained in school █
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█. I have been seeing, inpatients and out patients cases, quite a number of them, out patients cases being between 30-60 patients a day, on the wards of course those are inpatients care, that is following up the management of patients that have been admitted in more severe cases or diseases and discharged as they improve, this has been mainly facility based care, but rolling out also to outreach programs where we have been seeing, following up cases, case identification, supervision of policy implementation and various activities, and as well of course also subscribed to me by my superiors

Interviewer: okay, so how long have you been working at the regional referral here?

Respondent: I have been here since █

Interviewer: okay, so those are █ years?

Respondent: yah [REDACTED] years.

Interviewer: okay, so you talked about the patients you see, you talked about the numbers you see 30 to 60 patients, how about their age, which age do you see specifically and what are the common illnesses you see in these patients?

Respondent: this facility is a regional referral hospital, being a regional referral hospital we see a combination of patients that are referred from other lower facilities but also patients that are walk in from the nearby environment or the nearby catchments that are served by the hospital, on that basis, the outpatients care, the department in which I am in, is more of general practice, general practice means we see every patient as and when they come in, and that is very broad, we also see these patients, regardless of their age, so every patient that enters the hospital regardless of age sex regardless of the disorder they have, they are seen in the outpatients department. The only exclusions after is for patients who are severely ill and have to go straight to the emergency section because they cannot sit in the waiting line at the outpatients department, on that basis means I see patients from virtually two days of age to the eldest, yah so some of these patients for example neonates are brought by their mothers who had actually delivered them either in the village or in the lowest facility and have a problem and comes straight to OPD of course it is our duty to identify very fast during the triage that these are babies or neonates that are very sick or children who are very sick with different disorders, we see all illnesses, all the illnesses, the common infections, the common bacterial protozoa infections, viral infections that affects many parts of the bodies, so we are looking at diarrhoea infections, chest infections, we are looking at malaria, brucellosis and enteric fevers, skin disorders, so we are looking at all bacterial infections whether mild or chronic, we are also seeing increased number of non communicable diseases amongst the patients usually these are valid and also vary depending on the age, the non communicable diseases include those that are cardiovascular, hypertension, heart failure, diabetes, usually paediatric, adolescent and adult diabetes, we are seeing age related disorders, they are quite a number, very many, the list could be endless

Interviewer: okay, so now tell me a bit about your training in rheumatic heart disease; did you receive any specific training during school about rheumatic heart disease, in the school time?

Respondent: of course during study in the medical school, we are taught about diseases like rheumatic heart disease, and because frequently in the field, we have heard of course being a hospital care a number of CME Have come up and quite often not occasionally, diseases like

rheumatic heart disease are have been mentioned, probably the CME could have been cough of which rheumatic heart disease was a differential or rheumatic heart disease itself or heart diseases in general where rheumatic heart disease was a differential diagnosis, so I have had training in school but also occasionally as CMEs

Interviewer: so occasionally the CMEs that is after graduation, have you had a specific training on rheumatic heart disease after school?

Respondent: No, I have not had a specific training for rheumatic heart disease and so to say if it has been a training that is specific it has, I think I will end there that I have not had the training that is specific for rheumatic heart disease.

Interviewer: okay, so how many patients of rheumatic heart disease do you see per day or per week or in a month?

Respondent: it's quite a hard question because one, of the many patients we see, many times we end at, speculative diagnosis, and because we do not get the return result, to tell us whether this diagnosis was rheumatic heart disease, I cannot quantify the number of patients that have a rheumatic heart disease I have seen either in a day or in a week, I can only end up telling you, how many I have suspected to have heard rheumatic heart disease, that is one. Two, the figure is also variant, the figure also varies because it depends on whether in the out patients department I am seeing the adult outpatients or the paediatric out patients, there are more cases of on rheumatic heart disease in the paediatric OPD than in an adult OPD. On that basis I would say if I was in the paediatric unit, the Mondays are heavier than the Fridays or the Wednesdays, Mondays, Tuesdays are usually heavier days, I would base my diagnosis or my differential for rheumatic heart disease on how many cases I see for cough, and how many cases I see for cough with the major criteria, the diagnostic criteria, I think it's called Jone's criteria, the triage of fever, joint pains, nodular, migratory nodular pains, swellings, also sore throat, so on that basis, how many children would I see in a day in the paediatric OPD presenting with the major diagnostic criteria, I believe on a Monday those would be five, on Tuesday, a similar number 5, Wednesday fewer, about three or two, Thursday the same, so Monday to Friday that would make it five five, that would make it 16 to 17 cases a week.

Interviewer: okay, right now I want us to focus on rheumatic heart disease, in the past recent have you encountered any whose diagnosis has been made a rheumatic heart disease patient whether inpatient or outpatient?

Respondent: definitely yes, and I think that yes has been augmented by the fact that you have been here doing this research, initially we were incapacitated with having the ability to do Echocardiograms, the ability to do ECGs the ability to do, Aspartate aminotransferase (ASAT) titers and many patients were financially incapacitated and were not able to do CBC or hemogram so some of the tests that would request for, so I think in your presence with this study, there has been an increase in our ability to diagnose effectively a rheumatic heart disease

Interviewer: now I am interested in what you were taught maybe in school about rheumatic heart disease, what's your understanding of the causes of rheumatic heart disease?

Respondent: rheumatic heart disease it doesn't come inherently as, I would say, rheumatic heart disease is not actually caused immediately by a pathogen, the patient gets down with a bacterial infection from streptococci organisms which presents with an acute flue like illness, with fevers, sore throat, joint pains, sometimes swellings that are migratory around different aspects of the body and those are the major clinical signs along with others minors like vomiting, body weakness and others. This infection resolves with or without some treatment in some children, the infection usually affects children not adults but is not limited to children, some adults can get down with a streptococcal B infection that will be, so during that phase we call this an acute rheumatic fever, its either acute, the term acute is relative, because it could be sub acute it could be acute depending on how severe and how fast the symptoms come following that infection as the disease weighs out with or without treatment, and depending on the host's immunity, there is formation of an antibody complex, it is this antibody complex that begins to erode and damage the capillary bed of the different target structures in the body, more specifically the heart, so it's more notable with the heart and the kidney, so the patients manifest with rheumatic heart disease when they begin to manifest with the signs resulting from valvular damage. Those would be, difficulty in breathing, body swelling, heart palpitations, at that time they are still either having the fevers or the Febrile illness that initially came up with rheumatic fever.

Interviewer: so, are you aware of a link between a sore throat and RHD?

Respondent: yah, aah repeat that, I am really not so sure

Interviewer: are you aware of the link between a sore throat and rheumatic heart disease?

Respondent: I believe a sore throat is one of the main signs of someone having a streptococcal B infection and of course one of the signs of streptococcal B infection is sore throat, but from

the sore throat, it's also one of the clinical diagnostic manifestations we use to know that this person could be having acute rheumatic fever or not.

Interviewer: and what were you taught can be done to prevent RHD

Respondent: RHD, of course for starters, prevention is better than cure, the first thing would be prompt treatment of any cough, or sore throat with penicillin, basically that is it. Prompt treatment but even then increasing the awareness of the communities on diseases like rheumatic heart disease and rheumatic fever.

Interviewer: so what were you taught are the treatment options of rheumatic heart disease?

Respondent: I was giving that as a general one, the first one of course is early diagnosis, and early diagnosis means if the patient has been treated in a health facility, and the facility is not able and the patient is not improving on penicillin, and they have been referred upwards, so the health worker has to refer the patient upwards for more investigations at a health facility, the patient is seen and emphasis is put on being able to do some blood test of which also titre is a basis. Antistreptolysin titre is one of them, is the major one, then the others are a full hemogram that would show features of bacterial infections the other one is ESR, because remember there are differential diseases that would also cause the signs that manifest like rheumatic heart disease, so at that point of diagnosis, we move into the treatments, the main treatment is of course specific, we treat acute rheumatic fever or rheumatic heart disease with penicillin, and a long term penicillin, you give Benzathine, that is penicillin G, but we used to give pen V which seems to be weaker now, we can also give Amoxicillin but depending on the patient's ability to adhere to treatment we tend to stick to long term injectable like penicillin G, if a person is penicillin sensitive we can go down to Erythromycin. That is more specific treatment, the supportive treatment of course is analgesics and supportive treatment also targets the heart, where we give digitalis, we give beta blockades, we give various treatment that are specific to the condition of the heart. Then of course with severe, while we treat the infection we also move on to prophylactics to prevent endocarditis, so this patient stays on long term penicillin to prevent further valvular damage but with severe valvular damage then we begin to consider referral for surgery.

Interviewer: okay, that's really great and what is your understanding about the long term prognosis of rheumatic heart disease?

Respondent: understanding of the long term prognosis, this is a relative term depending on one, the access to care and two the capacity of the patient to consistently afford the health care interventions so initially the prognosis would be a life long illness, a lifelong debilitating illness with between five to ten years but again depending on the onset so if we are talking of childhood onset of about five to six years of age, rheumatic heart disease does not have prognosis of over 20years in a typical African setting where the patient has poor access to health care, that one, so 20years, we are looking at if a child is 5 to 6 years, we are looking at 10 to 15 years from the onset of the disease and again that is affected by the severity of the illness and the extent of the valvular damage, so prognosis basically is a relative term and it is case dependant on those factors onset of the disease at what age, the severity of the disease and the extent of valvular damage in the heart and if there was rheumatic heart disease anyway and also the timing of when was the diagnosis made, when that illness came up

Interviewer: okay, that's great, now I want us to recall the very last patient you saw of rheumatic heart disease, do you recall any, the very last patient you saw with rheumatic heart disease just of recent.

Respondent: like I said, it is hard to recall because I have been operating on the basis of differential diagnosis so it is hard to tell but the last patient I saw if it's okay for me to say this in this interview, was a case I sent to you, it was an 11year old boy, I saw and met your criteria, he had fevers, he had sore throat, he had joint pains, he had been treated on and off but without improvement, so I referred him to you, you started the tests good enough you came back and told me that he met the criteria, some tests have been done, the echo and ECG were highly suggestive and of course we were waiting to have an aso titer done , this has been an interesting case because he had been treated several times, I mean with the penicillin which are the main treatment for rheumatic heart disease, unfortunately these have been short treatments, five dates treatment for the cough but without the target intention for the treatment of rheumatic heart disease so the boy kept coming down with the joint pains and fevers, that's the case I remember.

Interviewer: okay, so you said he was 11years old, was he in school?

Respondent: No, he had been in school the previous term but this term, he had studied for a week or two and came down with an attack on this febrile illness.

Interviewer: okay, kindly summarise for me signs and the symptoms he had, you had talked of the sore throat, how did he present when you received him?

Respondent: actually he presented as a case of recurrent joint pains and tonsillar hypertrophy and as I took my history I noted from the parents that he had recurrent episodes of oral pharyngitis manifesting as a sore throat, pain on swallowing and hyper salivation, these episodes were associated with fevers, being a child it had been difficult for him to talk about the joint pains, so the mother, when she found out the joint pains she was being keen and another time she really found out when she was telling him to walk and run faster and he was saying he had some pains which she could not allocate at that time, so it was basically presentation of recurrent tonsillitis.

Interviewer: so are these our patients generally aware of the link between sore throat, rheumatic fever and rheumatic heart disease?

Respondent: definitely not, at that time when they come in the diagnosis sense of; because when the patient is brought, usually a child is brought by the mother, the awareness is on the connection of co-currency, either co-currency or precision, a mother will tell you that this child first developed a fever, had sore throat around the same time and cough with flue and later got joint pains, but sometimes between this time and a few months later when they manifest with a heart symptoms, the mother might not easily correlate, so the correlation a mother or patient says is just by a fact of how some symptoms follow each other or how some symptoms are related to each other but not as part of the diagnosis that this fever, is rheumatic heart fever or rheumatic heart disease in that sense.

Interviewer: okay, so do you think these patients are good at follow up and adherence, you have talked about giving them penicillin for this disease, so what do you comment about the follow up visits and adherence to the drugs?

Respondent: that is case dependant, it is very case dependant on many factors, one, if a patient has had a severe illness and they are really scared and anxious about the disease they are more often going to be serious about coming back for a follow up or adhering to their treatments, so however or even when they are serious and are committed to their treatment that has been given or a management plan a healthy worker has given out, they have incapacitation in various ways, the main one has always been the financial incapacitation, when the person cannot afford either the treatment, the second one has always been the distance, the distance from the current facility where the diagnosis for rheumatic heart disease has been made and to couple along with that, the distance, again the work, what we call the work home environment. These patients are usually children who are brought by their parent, their parents are working, even when they

want to come to hospital, they are not able to come, even when you tell them, reason being there is a negative influence, there is what we call control influence from their work stations, so even despite these, we try our best to schedule the appropriate days for the patients to come back for follow up. The biggest challenge is along those parameters. One the financial, two, distance and three the access to other factors that affect their access to care. For starters access to care can also be affected in this facility by a long patient waiting line so the patient is more often going to be hesitant to come back if he or she knows that there is going to be a long waiting line, so on top of financial issues the distance, the fact that many of these children are brought by their parents who are working and cannot afford to have them brought back every day or every time they are told to come. There are also those factors, long patient waiting time

Interviewer: so are these barriers, the ones you have started, are they the barriers patients tell you actually or they are the barriers you think?

Respondent: these are specifically patient based. These are patient based barriers that are a cross between what I see and what the patient says

Interviewer: okay, and what sorts of barriers do you passive, let's add on those ones you have told us, there are these ones they tell you they face but there are those you think you as the health worker, what are the barriers you think would affect the patient while getting care?

Respondent: the barriers that would affect a patient coming for getting care, if am to look at it from these views, I would say there are barriers that are patient based and those that are healthy worker based there are those that are facility based, there are those that are national, within the policy based, there are also those that are coming from the environment, so when you are at the patient based, the factors, I would believe that the one thing that the patient would tell me that is going to affect the ability either to come for the first time or the second time for follow up is going to be the financial aspect that they cannot afford the transport to come back or they cannot afford the money to do the follow up tests, it could be a full hemogram, it could be the second ECG, it could be a second echo. Sometimes you might not be able to afford the drugs when they are not in a hospital and we need to send them to buy the drugs either in the nearby or external facility so that is a patient reported barrier that I always receive, the main one.

Interviewer: okay, so now let us look at the local health system barriers which is where you were actually going, so I am going to mention here some pieces you tell me which pieces are working for you and which are not working for you so we have...

Respondent: by the way, sorry if I would take you back, on the patient other barrier that I have not talked about is poor health seeking behaviour, superstition, patience bias for political reasons, and there is also what we call dependency syndrome it's a big barrier, dependency syndrome in the African setting is having a child or a woman who cannot go to the hospital when the husband or a father or mother has allowed them to go to the hospital, the other one is of course ignorance and lack of knowledge about the disease, which makes them have late decision to go to the hospital and also resulting to late diagnosis, I am sorry to take you back, I had forgotten that one.

Interviewer: it's okay actually, elaborate more about superstition what do you mean by superstition?

Respondent: superstition, different cultures, different villages, different communities is the term I would say for what the scope and the communities we have that are served by a regional referral hospital, the diversity of the communities we serve basically is the one that tells us that there are people who come from all different sorts of religions, different levels of education, different backgrounds, now it has been common in the past for different communities to have different superstitions, I would call it superstitions or how do they call it when someone thinks about, if someone has a wrong perception about a disease or a behaviour or an activity, I don't classically call it superstition but basically they are the myths, we call the myths about the disease in the community. Regarding sore throat and the fever in relation to the differential diagnosis of mumps, the different communities, people in different communities believe that if someone has mumps and sore throat, if you laugh at them, you also acquire the sore throat. In one way or another, it prevents further spread of the illness because children are not going to share a cup with this person who is sick but again they are also not going to go near this child and therefore laugh at them, so this myth of course prevents in one way reduces the transmission rate for a bacterial sore throat because the children are not allowed to interrupt with each other, they are not allowed to drink and share from the same cup and things like that but there are different myth, I wouldn't call it superstition, there are different myth about sore throat, about cough, about fevers, sometimes its extreme that if a child keeps getting the chronic illness, the recurrent fevers and then their health starts to deteriorate especially if they have rheumatic heart disease, the mother or the parent of this child might put a pointing finger to the neighbour accusing that neighbour for having indulged in witchcraft and bewitching this other person's children, so these are things we cannot ignore in cases of chronic care, endemic chronic diseases, diseases that have recurrent illnesses or recurrent episodes of illnesses

Interviewer: okay, that's really great, so looking back at the local health system barriers, we had talked about the administration and leadership at the district, here in this hospital, is it working for you? You are going to tell me which one of these pieces is working for you and which one is not working for you and you tell me why, so the first one is administration and leadership of the entire hospital, is it working for you?

Respondent: in relation to...

Interviewer: to providing care

Respondent: yes, yes it does

Interviewer: okay, explain for me because we are looking at the local health system barriers so we are starting with the administration at the hospital, is this piece working for you, you said yes, how is it enabling you to give the care that you are giving or how is it a barrier to the care that you are giving patients at the hospital?

Respondent: it is two forward because I would say yes and no, administration leadership it is a yes because one, we as staffs in this institution we are working and some of the things that we need are provided, we have furniture, we have lighting, we have a reporting mechanism, we have a good referral system internally, our lab is up but there are some system challenges especially one regarding the responsiveness of the administration or the leadership to certain gaps when they are reported so it would be a yes and no, administration and leadership within the hospital has provided facility and the instruments that we need, the challenge is that this is not consistent when it comes to the drug side and the lab side

Interviewer: okay, so how about the funding for health care in general and rheumatic heart disease in particular, is the funding working for you?

Respondent: of course at a more national level policy implementation, the approach has always been to do the smaller things that won't serve the greater population, so all services coming in into the hospital are more of PHC based, when you go to the drugs, the drugs are what we call essential drug list, so this is for the bigger or a wider population and it's the same when it comes down to the lab what we call a diagnostic activity that are the basic capacity for drugs for treatment, for diagnosis is always offered out or ruled out by the ministry at a basic level and there after the funding is wanting so we are able to find out that we could do ESR, we could do throat swabs, we could give amoxicillin, or penicillin which are drugs on the essential drugs list, we could give health education sessions, all of these are primary basic

health care provisions but at a certain point, when it comes to doing full hemogram let's say in the lab, when it comes to giving penicillin that have Clavunate like Amoxiclave, when we come to doing Echos, ECGs and other diagnostic tests, when it comes to ruling out health education sessions, repeatedly into the community or through a media platform like a radio where we have to pay for that, these are gaps that are lacking, inherently, in part this comes from administration but it also comes from the higher leadership of the country and the commitment what we call the will, politically

Interviewer: Okay, so looking at the medications, you talked about the essential drugs, so medications particularly these ones for rheumatic heart disease, Benzathine penicillin, anti-coagulation drugs, heart failure drugs, are they enough, do you think they are enough, is that piece of medicines working for you?

Respondent: in theory these drugs are working in practice there are gaps, one, in the consistency of provision or availability of these drugs, two on the basis of awareness of the health worker that is prescribing of the drugs, I personally find that I get gaps at times in the congenital medication either because there is no refresher course that would update my knowledge about either the side effects or the importance, medications or the mechanism of how the drugs should be given especially in respect to children, so drugs work for me in theory, in practice there are issues about consistency, availability and also for some of those medications, like I told you, the anti-coagulants.

Interviewer: Okay and you had talked about the diagnostic, so let us particularly look at echo cardiograph, and how is it available for these patients who have rheumatic heart disease at this facility?

Respondent: that is relative because they are either children or adults, for the adults there are is an echo cardiogram in which a patient has to pay 50,000ugshs. That is quite a lot of money, I would say only 50% of the patients can afford that amount on the day when they come on the few weeks when they come and present. On the very day when they present in the hospital and the reference for echo is done, only 25% of the patients I send can afford to have an echo, many can afford to come back, that's one, and two the echo is being done by one of our physician and this is only done on specific days of the week, which is only two days I think that is on a Tuesday and a Thursday and this greatly hinders this basically puts a big barrier on access to the echo cardiogram services, that's for the adults, for the children there is an echo cardiogram some paediatricians have been trained on the paediatric ward, I am not conversant with the

days when they work but I think it is a similar challenge when it comes to the costs and affordability of having an echo, ruling out free echo services on a daily basis or more frequently during a week will be a long way in health treat and manage of patients with rheumatic heart disease I definitely think.

Interviewer: okay, and let us look at the health care workers in terms of numbers and the qualifications and the waiting time and the quality of care, so let us start with the numbers and the qualifications and the waiting time and the quality of care, so let us start with the numbers and the qualifications in this facility, is it working for you?

Respondent: numbers and qualifications, by department or by hospital in relation to the what?

Interviewer: in relation to the care of rheumatic heart disease and the general health care at large

Respondent: when it comes to numbers, when it comes to numbers, definitely the numbers are short, there is a severe shortage, there are severe shortages in certain areas of the hospital, in general we need to have more staffs for each of the institutions and for some of the departments the urgency and need depends on the area, for example the outpatient department needs more clinicians than the nurses, that's one, two as the qualifications goes higher, the need actually and the shortage becomes more drastic, there is a need for more health workers that have a higher cadre, a higher qualification, paediatricians, physicians and specialists and as we know theoretically, the ratio of the physicians or the higher the qualification is to the patients is far much worse, is far much bigger, on that note I would also say that there is a need to scale up speciality in relation to the management of rheumatic heart disease, virtually no health workers that are specific to the treatment of rheumatic disease in Uganda, so rheumatic disease as one of the diseases is treated by a general specialist not a specialist that is meant to have studied higher up and specialized in management of that disease in particular

Interviewer: okay, and let us look at the waiting time of our patients how is it?

Respondent: like any other institution, the waiting time is bad, it's always above 30 minutes, on a Monday it goes to three hours, 4 hours. In the paediatric section, paediatric out patients in this hospital, the waiting time is also bad, it is far worse off because of the lack of triage mechanism, that would triage a child with a minor complaint versus a child with chronic complaint, some children come from very far, they are referred into this facility with suspect of rheumatic heart disease and unfortunately they sit in the same line with a child that has

developed a cough yesterday, so the inability to triage out such cases is of concern and again this is made worse because there are many children and many children with a long waiting time it affects the ability for a case of rheumatic heart disease to be seen promptly, coupling on a previous point we had four numbers where a health worker is over strained, sometimes there is little time for a health worker to give a clear assessment and evaluation of this patient with rheumatic heart disease when they get to the station, it's a general problem.

Interviewer: so averagely you think a patient waits for how long before they get to see a clinician?

Respondent: like a said it depends whether we are talking on the paediatric section or the adult section, we had an assessment survey on patient waiting time, and patient waiting time seems to be fluctuant, its worse on a Monday and Tuesday but it's lighter on the other days of the week, that's one comment I would make, two, it's also worse during certain seasons, so the patients attendance to the health facilities, fluctuates with the seasons when they are high, malaria cases, when there are rainy seasons, I think its relative I can't give one figure for patients waiting time, the average right now in this month would be 45 minutes.

Interviewer: okay, how about the quality of care you give to patients, do you think it's working for you?

Respondent: quality of care is a broad term, it's a very broad term in terms of what the patient wants, what the patient should receive and what the health worker should give and what the institution should give, so quality embraces so many things but I would say it in general that in terms of competence of the health workers to do their work from the basis of skill set and knowledge I think I have no problem with the quality, in terms of the health workers having the necessary requirements to perform their duties well, I have some concern, if I would give you the percentage of the bad to good side, I would say we are on the bad side, if bad is 0 and good is 100, we are at 40% regarding health workers having the requirements to do their work in the clinical sense, when it comes to the lab, health workers do not have the requirements to do certain tests, and on the zero to 100 bad to good, I would say 35. In terms of the institution providing an environment for care I would say we are doing very well because patients come, they are directed where they go, they have sitting slots, the departments are there, wards are available, for those who are admitted, the space is there though sometimes there are issues about the bed numbers or if the numbers of patients are over whelming, so quality of care in general is fair.

Interviewer: okay, so let us look at the health medical information systems in these patients for both out patients and in patients, is it working for you, Medical record system?

Respondent: it was not working one year ago, we have a big problem with the data system within the institution, there is a lot of duplication of data, various data collection points that are not centralized, the system is not working in unison within the hospital, however there are steps that are being taken to streamline a complete robust data system within the hospital, at OPD currently we are phasing from a manual to an online patient registration system and we having definitely challenges with this system because it is still a trial system so I am not comfortable with it right now within our department, the outpatients department. In the hospital in general, there is a basic what we call HMIS system, it's a reporting system where all wards and departments report information to the central records office and this is ongoing and we are comfortable with that, the data is collected. The challenge has been the fact that patients enter this institution at different points, and if a patient entered going to the outpatient department was given a number 001 and another patient went to emergency was also given 001 and another patient was entering the hospital straight to the obstetric care to the labour ward for delivery was also given 001, you would have three patients with one number 001 but no one would be able to know which patient is which because we do not have a patient identifier, a unique identifier number for these patients when they enter the hospital

Interviewer: so talking about registration, do we have specific ARF and rheumatic heart disease registers in this hospital for patients?

Respondent: we do not have these registers in the other departments I am not aware about whether there is one in the paediatric department, I am not aware, but with the system based tools, data collecting tools, there is no unique identifier tool for ARF or rheumatic heart disease.

Interviewer: so how about the guidelines and protocols for rheumatic heart disease care and also comment about the referral pathways of how you refer these patients from one specialist to another, do we have guidelines and protocols for rheumatic heart disease care?

Respondent: yes we have, all clinicians in their rooms have the Uganda clinical guidelines so treatment goes according to the Uganda treatment guidelines, however while these guidelines give suggestions and protocol on how the cases should be managed they are the practical incapacitation at one making a diagnosis so if one is not making a clear diagnosis on the basis of either aso titer , on the basis of echo and we are only making diagnosis on the basis of clinical suspicion, definitely I believe that this one is a hindrance, however within this institution, I am

comfortable with the clinical diagnosis criteria we are using and I am also comfortable with a referral system because we refer as general clinicians, we refer all children under 12 years of age to the paediatric clinic which works one a week on Wednesday and here there is a paediatrician to see and attend to these patients. From there on, the paediatrician might decide to send to a senior paediatrician or to send to a senior health worker at that cadre level and admit for inpatient care, so I am comfortable with the referral system and the protocol we are using

Interviewer: so now looking back in these things we discussed, so you are saying that the guidelines and the protocols and referral systems are working for you, right? We are going through them again to see which ones are working which ones are not working and which ones are fair.

Respondent: and we need to be specific, I wish I had the Uganda clinical guideline here because it's the one I used, but if I have my UCG or my table and I met a patient who I thought had a rheumatic heart disease or acute rheumatic fever and I read through those guidelines on my table, I believe they would help me a lot in helping my patient, two after the decision is taken to help these patients according to the Uganda clinical guidelines, I would start to meet challenges, one when I order for a test let's say an aso titer , a CBC and Echo or any other of these tests and the patient cannot afford to pay for either of the tests, at a later stage, the patient might not be able to afford the treatment if we don't have that treatment available at a tertiary stage the patient might not be able to come back for follow up on a day that was subscribe either to see a specialist or referral or to be reviewed, so the system challenges begin to come up at a practical side but not from the theoretical side of the protocol and guidelines.

Interviewer: so in other wards you are saying that the guidelines are working for you but the diagnostics are not working for you

Respondent: but the diagnostics are not working

Interviewer: okay, the health information system and the records you said they are 50, 50.

Respondent: I cannot say 50, 50. I know these are things where it's a black or white position, if data is meant to be useful, it should be full data, complete data consistently generated, consistently assimilated and analysed for it to be of any use, so I cannot say 50, 50. I would say our data is not complete, our data is porous, our data is not well assimilated and analysed, and our data is not collected on time so data is not working for me

Interviewer: so it's not working for you, and for medications, BPG anti-coagulation drugs, anti failure drugs, you said they are working for you?

Respondent: some

Interviewer: you would give it 50?

Respondent: that question is relative on whether I am comfortable with the drugs as prescribed in theory, that one I am but availability no

Interviewer: so it's working for you

Respondent: some are working for me, some of the drugs are working for me but the challenge is I don't have consistent refresher on the category of drugs that are written there, what we call the anti-coagulants.

Interviewer: and the funding in general of the health care system, it is working or it's not working?

Respondent: it works at a basic level, at a basic level where provision of basic services are provided, at a higher level, that falls short

Interviewer: so you give it a yes or no?

Respondent: I cannot give it a yes or a no because I have told you at a basic level, provision of health care at a basic level, the staffing but when you begin to go into specialized care the health service delivery falls short

Interviewer: and the administration you said that one is working

Respondent: the administration is too forward, the administration is working but there are also some leadership challenges but I would still say the administration and leadership within the hospital is okay

Interviewer: so let us go to the last batch of the questions, the perception of patient outcome generally do you think these patients get the care they need, clearly we are talking about RHD patients, especially surgery, and do you think they get the care they need?

Respondent: our patients get the initial treatment, but when it comes to surgery, our patients do not get the care totally but a very small percentage, I can't quote anything but in subjectively I can say under five percent can afford the surgery in this area, can afford the surgery required for management of rheumatic heart disease.

Interviewer: and let us look at the patient's safety, do you think there are any patient's safety and quality of care concerns for example have you heard preventable deaths in the hospital, have you seen a death occurring and you are like for sure this shouldn't have happened?

Respondent: okay, in relation to rheumatic heart disease or in general?

Interviewer: in general

Respondent: no, I saw one maybe, I saw one, the patient had severe hypoglycaemia in diabetes and well these are factors that are out of the hospital's control because this is a person who gave themselves an injection with insulin, forgot to eat and taken some alcohol, slept thought they would wake up, they did not and by the time they found out that the person was unconscious they were in the village, the first primary health care worker did not respond to the diagnosis that this could be hypoglycaemia, managed different things and added the quinine and referred the patient here, by the time the patient came, they were very comatose and I thought that this was a problem with diagnosis, it was a preventable death. That one, there are also others that have happened but I have not been there, neither at the emergency section or down on the wards, I cannot speculate to say something which I have not been there present, that one is one case that I saw.

Interviewer: but do you think there are many patients dying in the community without actually presenting to the hospital for care?

Respondent: in regard to rheumatic heart disease or in general?

Interviewer: generally

Respondent: definitely yes

Interviewer: why do you think so?

Respondent: it has always been a barrier of ignorance, lack of knowledge, poor access to health care, poor health seeking behaviour, and financial incapacity, if we become more specific and go to either obstetric care, paediatric care, then that's where I will be more specific

Interviewer: okay, so as we wind up now, in your own opinion, are there one or two most important things you think ministry of health can do to actually improve the outcomes of our patients?

Respondent: if it is regarding rheumatic heart disease, I think the ministry of health needs to secure funding internally, but it will secure funding after prioritizing and ruling out a basic treatment care package for rheumatic heart disease nationwide, this care package should include, one, an Aso titer, the ability to have echo to probably attaching a CBC test and then ensuring that basic treatment for rheumatic heart disease is available. If this is going to be very expensive, some facilities have these on a private basis, it will become easier for the ministry of health to ensure that all facilities have prioritized RHD by creating a department for management of rheumatic heart disease or acute rheumatic fever in their institutions. Having a department also increases the ability for sensitization and awareness job creation among the communities, rolling out other facility based and community based facilities, I think that is the one biggest thing, prioritizing through policy formulation by the ministry, prioritizing the need to create a rheumatic heart disease department within the ministry and then following all the system tyre downwards and it is then these departments that will prioritize how and when tests can be done and then health workers will be trained and refresher courses done how and when patients can be sensitized and referred through a system that would help patients get managed better and faster.

Interviewer: any other?

Respondent: that's the main one, because once this one is there, then the political need will come up. Of course it will secure secondary funding and the other but it still starts with prioritization

Interviewer: do you think you have any other thing you want to comment about before we close?

Respondent: I will say, I am very happy to have taken part in this interview but again I am even more happy that your presence here as an ARF study has greatly helped the patients that have been seen during the time, because I am very sure that 90% of the patients you saw, would not have afforded to have some of the research study interventions that you rolled out especially the aso titers, the treatment and care, the Echos and ECG tests. And I am most very happy that the staffs in this research study have been very supportive to us, they have been very good, they have been very professional and I would say good luck to them and also say thank you to the study investigators because this is a critical area that has been lacking and the need is there to have this intervention rolled out regarding rheumatic heart disease, prevention and control, yes.

Interviewer: okay, thank you so much doctor for your time, we are grateful

Respondent: you are welcome.

Participant ID	HW010
Age	■
Date	18th November 2019
Venue	Mbarara regional referral hospital-pharmacy stores
Interviewer	

Interviewer: today is the 18th of November 2019 and we are at the pharmacy stores of Mbarara regional referral hospital, thank you sir for being here with us and allowing to participate in this interview. My name is and like I told you, I work with Uganda heart institute and in the project of acute rheumatic fever study, so you are welcome

Respondent: thank you

Interviewer: and tell me a bit about yourself, how old are you?

Respondent: let me begin with my age, I am just ■ years old

Interviewer: okay, and what are your qualifications?

Respondent: yes my qualifications are I have ■

Interviewer: okay, where did you train?

Respondent: I trained from ■

Interviewer: and when was that?

Respondent: that should have been from ■
 ■
 ■
 ■

Interviewer: how long have you been in Mbarara regional referral?

Respondent: Mbarara regional referral I think I am in ■ years I think, I should approximately be completing my ■ year.

Interviewer: okay, and what are the demographics of the patients you see at this hospital ever since you came, which age groups of the patients do you see?

Respondent: the patients we always see at the hospital are almost from from zero age to the oldest which you can never know, that's the kind of patients we see, and you see they are from different places, there are even patients who come from Tanzania, refugees, others are close to Kisoro, everywhere, Masaka also refers here, Fortportal refers here so the patients are many from different places that are not even in our catchment area.

Interviewer: okay, and what are the common illnesses in these patients you see, depending on the group, do you remember the common illnesses they have?

Respondent: if I am to see, the common illnesses keep on changing like, for last year, there were these other common diseases, maybe someone comes presents with maybe UTI and PIDs, ulcers, upper respiratory tract infections, those are the common ones we see at OPD, then the different wards, now like at medical ward, there is the common patients we always see maybe having heart complications, hypertension and all that.

Interviewer: okay, so tell me a bit about your training on rheumatic heart disease have you received any specific training during school about rheumatic heart disease?

Respondent: rheumatic heart disease, I heard it in school, and if I am to remember, I think it could have been given so much time during its being taught, I might not remember the nitty-gritty time has gone I might not remember but at school, were taught about rheumatic disease but since I started working, I have not heard any training, maybe refresher training of rheumatic disease.

Interviewer: actually that leads me to my next question because I was going to ask you that after graduation have you heard any specific training about rheumatic heart disease?.

Respondent: no I haven't heard any training of rheumatic heart disease.

Interviewer: okay, but have you seen rheumatic heart disease patients ever since you started working especially here at this hospital?

Respondent: on the wards, for the time I have been on the wards, I can't recall exactly, but I think I could have seen because due to the nature of my work, you find that there is so much, I am responsible for supply chain, I am responsible for training staffs, I am responsible for administrative issues, so at times I find that even when I am on ward for a shorter time, my patient to patient interaction time at times is always so small maybe just on a few spot checks

but I think for rheumatic heart disease patients I could have met him those first days when I was trying to practice in the medical ward.

Interviewer: so what's your understanding of the causes of rheumatic heart disease in your own understanding?

Respondent: at first like I have told you, from the basic local explanation that you have been using to explain to people, we believe that rheumatic heart disease is; the walls, and how people say it in Luganda “ebisenge byomutima babilidde” though the actual things that we are taught in class are that maybe those other valves of the heart are eaten up.

Interviewer: Okay do you know what causes that to happen?

Respondent: from what I learnt I learnt in school, the little that I could recall would be that when you have simple disease, maybe like a simple cough that is not treated, they told us even a mere infection, or even a nose infection, that alone can get its own way within a blood stream to reach the heart and you get that kind of the infection

Interviewer: okay, are you aware of the link between a sore throat and rheumatic heart disease?

Respondent: now that physiology that happens there, is what I can't recall properly

Interviewer: and what were you taught can be done to prevent rheumatic heart disease?

Respondent: from what we were taught, we were taught that, where resources are available in a resourceful environment mostly they could do a throat sore by maybe, they can be able to identify the micro organisms but in these other facility settings here in Uganda they told us they never take any sore throat for granted, maybe they can go ahead to find out whether its viral or bacterial but make sure that every sore throat can be very treated any cough, actually any cough needs to be attended to because at times it can progress somewhere and its more expensive to treat rheumatic heart disease than the sore throat.

Interviewer: okay, and what were you taught are the treating options for rheumatic heart disease?

Respondent: rheumatic heart disease I think by then, if I am to remember, one stays on the treatment for antibiotics for quite sometime, it's not a treatment for antibiotics and if I am to recall, I remember they should have told us someone to be on penicillin for quite a long time, there I can't remember the exact time we were told.

Interviewer: okay, any other options or treatment options?

Respondent: because even if they are to do valve replacement and all that still that doesn't prevent you from taking those antibiotics

Interviewer: Okay and what's your understanding about the long term prognosis of rheumatic heart disease?

Respondent: what I know is, like I was saying, most of the patients that I have been meeting that I know their fate is always death but actually I haven't seen one who has recovered, I haven't met one who has recovered.

Interviewer: okay, let's remember those ones you have encountered, do you remember the last person you saw with rheumatic heart disease, can you try to recall?

Respondent: yes, it was a young kid

Interviewer: how old?

Respondent: it was around 9 or 11 one of the two ages

Interviewer: male or female?

Respondent: it was a male

Interviewer: how long ago was that?

Respondent: that could be around three years ago

Interviewer: was that kid in school or not

Respondent: he wasn't in school; actually he could have left school with parents saying that there is unexplained illness.

Interviewer: is there any other thing you remember about that child?

Respondent: the diagnosis was a problem by then, actually it was doctor she is the one who came and we were having that kid on ward, that's when she said this kid could be having such and such a problem, why don't we go for further investigations to find out.

Interviewer: okay as you saw parents of that child or any other parents who have children with rheumatic heart disease, do you think they are aware of the link between sore throat, acute rheumatic fever and rheumatic heart disease in your own opinion?

Respondent: No, for them they were just having a patient whom they were just keeping in the hospital, actually the unfortunate bit is that they had been hospitalized for two weeks on the ward with no proper diagnosis.

Interviewer: okay, so let us look at this child you remember very well, what were the symptoms this child was presenting with?

Respondent: for that young man, he had already grown too small, looking malnourished, there are some parts of his body that were darkening on his body and I saw, he was also having amm, I don't remember exactly but I am trying to draw the picture of that young boy.

Interviewer: okay, and do you think these patients are generally good at follow-ups and adherence to their drugs?

Respondent: I think if you well explain to them their problem and you tell them that this will be the solution and when they swallow the drugs they see a change within the first few weeks, they can adhere because by the time those guys came into hospital, it was just at the extreme end.

Interviewer: okay, so is the problem not explaining to these patients?

Respondent: that could be one of the cause, one if they don't explain to these patients, two, even these cultural beliefs in them, you can convince the patient, the response to treatment I don't know why it would always be slow, that one alone discourages patients from doing what, from taking these medications

Interviewer: is that from your own opinion?

Respondent: that's from my own opinion

Interviewer: okay, and for them what do they say, these patients, what do they say are the barriers they commonly face to getting care

Respondent: these patients, now like that patient he was coming from very far, maybe from Isingiro, I don't still remember, he had moved through several clinic, several health centres, several tradition healers to a point where by the mother realised things were too bad to bring him to Mbarara here, so what prevents them from getting health care, sometimes they find that the normal conventional way of getting treatment, they feel it's not healthy

Interviewer: how?

Respondent: because most of them think some of these problems they have are because of their cultural beliefs, that is one, two some people don't have money, some people are very poor, because even that patient was coming from a very poor home.

Interviewer: so you mean in this area people that are poor do not get the care, do not get treated?

Respondent: in this area people who are poor they get treatment, they all get treatment, but

Interviewer: elaborate more, what you mean by they don't have enough money

Respondent: by the time someone fails to treat a sore throat, you know there are things that we just see, now like a sore throat, it's not something that maybe someone spends his money on to treat, are you seeing, and not so much people will take time to treat a sore throat, they think it resolves on its own and goes, are you seeing, so when it progresses on something like rheumatic heart disease, really a few people can afford to do some of these surgeries even to keep on these medications for long, even a mere hypertensive patient finds it so expensive to buy his own medicine, even a diabetic patient, you find them crying after telling them that we have run out of stock of such drugs maybe they can try somewhere else.

Interviewer: okay, so now this moves us to the local system health care barriers, I am going to mention here some pieces, you will tell me which ones work for you, in terms of giving care to patients, and you will tell me some which do not work for you and you will tell me why, so let us start with administration and leadership at the district does it work for you here at the hospital, in terms of you giving services to the hospital?

Respondent: that one, it very much helps me because even if I ran out of something here, the district can support me, it can do redistribution of medicines and they get medicines so that one alone reduces my stock out period.

Interviewer: okay, so it is working for you

Respondent: for me it is working in good relationship

Interviewer: how about funding for healthcare in general is it working for you?

Respondent: the funding in the healthcare system is okay but the few challenges that are there, some of them could be the inefficiencies within the system, like maybe the human resources, if someone tells you to make an order for medicines and maybe I choose to make an order of

medicines that are irrelevant in the community, what happens is that I will have expiries what patients need, they do won't get it.

Interviewer: and how about the funding for rheumatic heart disease in particular?

Respondent: in particular, actually when it comes to ordering for some of these medicines, some of these things, we don't go to the nitty-gritty of every disease that now this medicine is for caring for these people with rheumatic heart disease no, we try to consider what is on essential medicines, that is one thing, two we try to focus on what is very vital and essential then some of these non-essential we use some kind of principals to quantify and be able to procure some of these medicines we have.

Interviewer: okay, I am interested in knowing those ones that are very essential that you add on the essential drug list

Respondent: you see now the things that are very vital, we ensure that we always have Normal Saline and try whatever it takes to ensure that there are always fluids because its something that covers a very big number of patients, two, there are things that maybe serve like, gloves, cotton, goose, those ones, I will always ensure that they are always bought, because that is like first line of defence, so alone all those would consume a lot of budget but I know if all these ones I buy them, they still cut across to patients with rheumatic heart disease, if a patient comes here and we give him some of the treatment still they will use some of these as vehicles to transport these to the blood vessels.

Interviewer: okay, so let us look at the health care workers, in terms of the numbers and the quality of care they give, do you think it's working for you, let's start with the numbers of the healthcare workers working in this hospital, is that one working for you?

Respondent: yes, the work load would be much bigger than the healthcare workers available, the work load could be bigger but I see, they always sail through.

Interviewer: okay, how about the quality of care that the health workers give, is it working for you?

Respondent: if I am to go to my department here, I am very okay with the quality because literally I have not had any challenges for the past three years, yes there is no perfect system, unless it is only in heaven, you can always have mix ups here and there, but you always try to fix them and things keep moving

Interviewer: okay, let's see about the waiting time of our patients, do you think it's working for you, are you happy with it, the waiting time?

Respondent: it could be even shorter like I told you the volume of work is bigger than the staffs so it can be shortened if the volume of work is smaller than the staffs.

Interviewer: okay, so you are trying to, for starters, how long does each patient wait before getting services here?

Respondent: maximally it would be like 10 to 15 minutes

Interviewer: that's what they wait for now

Respondent: yes, if they are many, 10-15 minutes

Interviewer: okay, and let's look at the medicines now, this is your department, particularly Benzathine penicillin, anti-coagulations and heart failure drugs, is that piece working for you are those drugs there?

Respondent: Benzathine penicillin is always there and sometimes it gets expired, yes

Interviewer: anti coagulation drugs?

Respondent: anti-coagulation like warfarin I think it has been out of stock for quite some time.

Interviewer: other anti-coagulation drugs, like cardiac aspirin?

Respondent: Cardiac aspirin, Clopidogrel, for cardiac aspirin is always available throughout, cardiac aspirin is among the essential medicine, so for that one is always in stock through out because it cuts across a bigger population of patients, so cardiac aspirin is always available but for things like Warfarin it's always on and off, Clopidogrel on and off.

Interviewer: how about other heart failure drugs?

Respondent: like Digoxin and all that? Yes Digoxin is always available, some are available some are not.

Interviewer: so does this mean that this piece is working for you or its not working for you?

Respondent: it is not working, I would be happy if I had everything, that's my mission I would feel happy if a patient comes in and walks away with all the medicine he needs but when he wants three and I give him two, I am not happy about it because some of the patients they are

going to swallow the two types and leaves out the third one and the therapeutic benefits is always small.

Interviewer: okay, I am interested in knowing actually why some anti-coagulation drugs like warfarin is not always there and it's on and off, what brings that?

Respondent: some of these drugs, you find that, they are not on the essential medicines list, so when they are not on the essential medicines list, you cannot order for them, that is one, two, the level of care, as a Regional referral, we are not a specialised unit like you see heart institute is in Mulago, for it will always have these medicines like warfarin and others to treat these heart diseases because they are already specialised in that, but now us as a Regional referral and Mbarara is so unfortunate because of its location, it receives those patients that are meant to be in heart institute but they would come here. That is what creates the inadequacy of the treatment that they don't have but for our level of care, what they need we have it.

Interviewer: okay, so the reasons are because it is not a specialized hospital and some of these drugs are actually not on the essential drugs list, okay and now let's look at health information medical record systems, is that one working for you here?

Respondent: the healthy management information system, yes it's working.

Interviewer: okay, let's look at the registers here, do you have specific registers for some diseases where you record for example, rheumatic fever, rheumatic heart disease?

Respondent: we only give time to things like HIV.

Interviewer: you only have separate registers for HIV?

Respondent: HIV, TB but these other ones it's a one register.

Interviewer: one register, okay do you have the guidelines and protocols for rheumatic heart disease care, here in your department?

Respondent: the guidelines we have should be what is in the UCG and maybe some other guide that I might have.

Interviewer: how about these other guidelines designed specifically within the department like for HIV or TB, those charts that are specifically designed for rheumatic heart disease, do you have them?

Respondent: there are guidelines we use, the ones in the UCG, that's what we follow plus what we read but as a department we have not designed that guideline in fact we are in the process of designing what we call a hospital formula, in that hospital formula is where we shall identify the common diseases that we always treat and what is our recommended kind of treatment as per what suites the setting that we are in because we have realised that some medicines might be working in Jinja regional referral but when they can't work on patients in Mbarara.

Interviewer: okay that will be a great idea.

Respondent: it's something that might take time but we are doing it through the medicine and therapeutics committee.

Interviewer: so we are going to go through them again, administration you said it's working for you?

Respondent: yes, administration at the district.

Interviewer: okay leadership at the district is working for you, funding for health care in general, you said its working for you, and the health care systems, numbers and the qualifications of the health workers and the waiting time for patients is working for you, and the health information system, medical records, you said its working for you, plus the registers, and the guidelines, it's also working for you, that's it?

Respondent: yes

Interviewer: alright, let's go to the last piece of questions now, do you think the patients get the care they need, especially the rheumatic heart disease patients?

Respondent: that is subjective to patient.

Interviewer: in your own opinion

Respondent: actually the patients who leave this place cured are more than, are far from they could even be more than 100 times, bigger than those who leave here with more complications to refer to Mulago for further management, so which I think they are getting the care they need, because if you have close to 400 patients a day, and you may receive a death of one patient or non, don't you think you are doing a good job, this is a very small percentage of the 400, so they must be getting good treatment.

Interviewer: okay, talking about death, do you have any patient safety concerns, quality of care concerns, for example, have you had any preventable death here?

Respondent: but I think every death is preventable (laughs)

Interviewer: there are those deaths you really see and be like, oh this person wouldn't have died, have you had those occasions?

Respondent: personally not.

Interviewer: okay, do you think there are many patients there in the community dying without presenting here in the hospital?

Respondent: that is true.

Interviewer: what do you think happens, why don't they actually surface?

Respondent: some of them could be believing like I told you these cultural beliefs, others might be thinking that when they take their tradition medicine it will work for them, others might not know even that they are sick, then others could be in the community and could be having some of these diseases, but when they go to these health facilities, maybe the lower healthy facilities, they don't find solutions, so they now get to know that even if they go for further management, there will be no solution to help their problems.

Interviewer: any other reason?

Respondent: some of them maybe could not be having money, I am not meaning money to pay, I mean money that could help to transport themselves to hospitals and someone cannot be lacking something to eat and they get money to present to hospitals, this normal one will first eat, then if they are to die the die.

Interviewer: okay, so poverty, cultural beliefs, ignorance because you said that some of them they might not know that they are actually sick, okay is that all you can think of?

Respondent: I told you five.

Interviewer: you told me five, cultural beliefs, poverty, ignorance of their diseases....

Respondent: others have a bias towards like I have told you, if they go to the lower health facilities and they fail to get solutions, they know they will never get the solutions

Interviewer: Now, the last thing in your own opinion, what are one or two important things you think ministry of health can do to improve the outcome of our patients

Respondent: in matters of rheumatic heart disease?

Interviewer: in general, you can talk about it in general even in this side of rheumatic heart disease

Respondent: one thing about is it should get more if ministry of health can see disease don't read books, you can see even of late we used to say that young kids don't get typhoid, isn't it but even we see these days young kids with typhoid, so there is much to invest in research, there is a lot to invest in research so that they can get the new trends of management of some of these diseases are even preventable, so there is that need of even sensitizing the community, and some of these very preventable diseases that could even be leading to some of these problems that we are having and I know that one will reduce on the cost burden of the health care system

Interviewer: okay, any other, apart from that?

Respondent: most of these diseases are preventable so if they can give those preventive measures which could be, like they have done with malaria, give out mosquito nets then do that and all that, then again sensitize, and for people who have had heart diseases like those hypertensions, those are preventable diseases, people who have diseases like maybe diabetes, yes it is genetic component but you can delay it, but all that comes on how you empower the community with knowledge.

Interviewer: any specific thing they should do as far as rheumatic heart disease is concerned?

Respondent: rheumatic heart disease being among the cardiovascular diseases that we are having, the only thing I can ask for is like the heart institute in Mulago but Mulago alone may not be able to manage some of these diseases because of the problem of numbers, these is an upward trend to some of these diseases maybe rheumatic heart diseases, so if at a regional referral if some of these units are set up and they are well equipped with whatever they need, this would not be a problem rheumatic heart disease would not be a problem.

Interviewer: that's great, is there any other thing you would want to say before we finish?

Respondent: nothing, that's is all I would want to say.

Interviewer: okay, thank you so much, this is participant WH010, thank you so much for accepting to be in this interview.

Participant ID	HW 011
Age	█
Date	19th /Nov/2019
Venue	Mbarara Regional Referral Hospital
Interviewer	

Interviewer: Today is the 19th November 2019, and we are at Mbarara Regional Referral Hospital to meet a Physician .Participant record ID HW011, you are welcome Doctor.

Respondent: (Coughs)... Thank you so much

Interviewer: (Clears throat)... Thank you for giving us the time to talk to you, so we are going to start right away aah. This study is to determine how to provide better care for Rheumatic Heart disease patients, (clears throat) and there are no right or wrong answers, so please be frank and share your opinions, the data we gather is very confidential and we shall not leak it to your identity when we are producing our reports, so kindly tell me about yourself, how old are you?

Respondent: ooh, thank you so much. I am a female, I am █ years old, and I am a physician and █
█
█
█.

Interviewer: Okay, thank you so much, so you said you are a Physician, how long ago did you train?, where did you train from, before becoming a Physician?, how long did you practice?, how long have you been a physician?

Respondent: █
█
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Interviewer: Okay, that is a very wonderful CV, and how long have you been working here in the regional referral hospital, where we are now?

Respondent: At Mbarara Regional Referral I started working [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED] Anything I left out?

Interviewer: No, that's actually great, so let's talk about the patients you see, what are the demographics of the patients you see in your practice and what are the common illnesses in general.

Respondent: That's quite interesting, In general we see patients from 13 years of age in our medical ward and basically because in Paediatric ward patients aged 13 cannot fit their bed as such since I came here six years ago, the practice is when you are 13 years and above you will be seen as in the adult medical side, so my patients ranges from 13 years old to 90 years old, that's a big range and among these patients, the 13 years old are really few, we do see patients in their middle age any younger adults and we see geriatric age like those who are more than 70, 80's and 90 years old, so since these are three different groups, demographically the diseases or the main conditions that bring them to hospital is also different. (Phone rings)

Those who are above 50 or 50 and above, we do see people with stroke in their early 40's and we see people who are HIV and coming with opportunistic infection and mainly meningitis, that is tuberculosis meningitis and viral meningitis like cryptococcal meningitis those are the most common in that age categories of 40 and above but also we do see elderly patients coming with hypertensive crisis for admission and those come with hypertensive heart disease or heart failure, so the younger population from 13 maybe up to 25, let me say below 25, we do see mainly infectious causes, others are coming really for a very short stay, maybe diarrhoea, others are having poisoning, you know due to social issues, then these are the age group when we see them with heart failure they are more likely of rheumatic heart disease. Yah, basically that is the range of patients we see, of course we see also patients with cancer, some different sorts of cancers, Leukaemia, lymphomas, five years ago we used to see a lot of Kaposi sarcoma patients coming with complications but nowadays maybe because the guidelines have changed to test and treat. Then we see less of that, yah.

Interviewer: So talking about RHD now, tell me a bit about your training in RHD, have you received any specific training while in school about Rheumatic heart disease, Undergraduate (Laughs)

Respondent: Alright, I did my undergraduate from Sudan, from Khartoum and sincerely speaking in Khartoum, we had a lecture of course about Rheumatic fever, Rheumatic heart disease, I remember in Paediatric even we saw a patient of acute rheumatic fever with Sydenham's Chorea and all that classic presentation, but in the medical ward, during my training as an undergraduate, we had less of Rheumatic heart disease, I can remember some of the encounters I saw, those patients, I had even for an exam, like two or three of them but they had by then had heart valve surgery done so they got replacements, that is when I tend to know of Rheumatic heart disease and Valve replacement as an undergraduate student, but to find a full grown up of Rheumatic heart disease, the way I see them in Mbarara, is really quite different from the time I was trained as an undergraduate, I think because the places are different, and the type of patients we see are different, maybe that is why, maybe I have not seen a lot of rheumatic heart disease only those who had their surgeries done.

Interviewer: Okay, so after your graduation, did you have any training about Rheumatic heart disease specifically, that is after graduation, probably during your...

Respondent: So, during my internship, I remember I presented a case of acute rheumatic fever because by then they make us present cases every week, interested cases, and I had a patient of acute rheumatic fever who was seen I think from a peripheral treated as arthritis, you know, because of these migratory Joint pain here and there, and that's when my eyes open again of acute rheumatic fever, and that was in south Sudan by then, when I came from Khartoum, when I was doing my Internship, but a specific teaching, except during CMEs in which we can discuss about Rheumatic heart disease and other types of heart diseases. But if you say specific training just for Rheumatic heart disease, I don't think so. Only just a case based teaching or bed side teaching just like any other ward round you do and, you find a case and discuss about it.

Interviewer: Ok...so how many patients of rheumatic heart disease do you see like per day or per week or even per month, and are these in patients or out patients or both?

Respondent: So we see both inpatients and outpatients with rheumatic heart disease and most of the inpatients ones are those who come in heart failure, or in acute heart failure or decompensated heart failure, and per a month, we can have a number ranging from 5 to 10, this

statistics is basically because of a study I have done here before looking at a presentation of acute heart failure in our medical ward so our enrolment was really between 5 to 15 per a month. And out of this majority are Rheumatic heart disease and these are very young people. And now in the clinic we have a clinic day, every last Friday of the month and we see between 20 to 30, and between these 20 to 30 who have been in care, we always have maybe up to 5 or 10 new patients into the registry. The patients basically they come from the surrounding clinics around or hospitals around because now they tend to know that there is a specific clinic for rheumatic heart disease so those patients are referred either from those hospitals or nearby clinic to come to Rheumatic heart disease clinic based on their Echo report from town or anywhere else or just based on suspicions of rheumatic heart disease because they are young and they have listened to a heart murmur, “please go to rheumatic heart disease clinic” and that is how we get our patients.

Interviewer: Alright, now I am interested in knowing what actually you were taught probably from the CMEs you have said you had, probably about rheumatic heart disease, what’s your understanding of the causes of rheumatic heart disease?

Respondent: mmh, of course right from the beginning, aah it’s important. so when we are undergraduate we focus on the history, right? So in history taking you don’t have to miss any history of sore throat, recurrent sore throat that’s associated with joint pain, fevers and things like that and knowing the cause is being group B streptococcal as the most cause for rheumatic heart disease or acute rheumatic fever and I think it has not changed since and the risk factors have still remained the same overcrowding and sometimes if your immune status is not fine you will get recurrent pharyngitis and in children tonsillitis, being the main cause for acute rheumatic fever due to the immunological action due to the antigens of group B strep., so the antigens pathophysiologically we know that it does not only attack the joints and the heart valves sometimes the kidney as well, so that's why it is always important to know how the kidney is doing, what's the colour of the urine and things like that.

Interviewer: You talked about the sore throat, which brings me to my next question actually I was going to ask you if you are aware of the link between the saw throat and rheumatic heart disease

Respondent: I think I have just answered it.

Interviewer: You have just answered that one, so what were you taught can be done to prevent RHD

Respondent: aaah the most important is proper treatment, when I say proper treatment; we know that it's still sensitive to penicillins and penicillins are the most available drugs being in a good health care centre like a referral hospital to health centre 2, 3 which are really led by nurses, penicillin is still there. So the most important is a proper treatment and the second thing is, if a child or whatever person with recurrent pharyngitis and has joint involvement so it will be better that they are referred to appropriate service provider so that they are screened and have their echo done, yah.

Interviewer: Okay and aaah what are the treatment options for rheumatic heart disease, what were you taught are the treatment options we have?

Respondent: So I think drugs which are available for rheumatic heart disease or acute rheumatic fever?

Interviewer: Yes, for rheumatic heart disease.

Respondent: now for rheumatic heart disease, it really depends on how many valves involved and what type of valves involved in that is there, so the treatment varies based on the function of the heart, you know some patients can have rheumatic heart disease with myocarditis or pan- myocarditis so these patients tend to have really very low ejection fraction and these ones you treat them properly as all the patients of heart failure with all the medication and evidence for heart failure and aaah, patients with maybe one valve involvement let's say mitral regurgitation if it is mild, severe or moderate, if it is severe and you have your LV cavities dilated then they might meet a criteria to get a valve replacement, which is a better option, if they are moderate and they can afford, maybe they can also have that done, if it is mild, you prevent every reoccurrence of pharyngitis and of acute rheumatic fever because even if they have already rheumatic heart disease they still have a chance of getting recurrence and that will lead to worsening of the existing valve issue which is there and it can make it really worse and that really brings us to where or why we give them penicillin prophylaxis, and from these rheumatic heart disease registry, early studies which are published we know that those who are taking their penicillin prophylaxis regularly take it better and those who did not they have poor prognosis including hospitalization and mortalities so it tends to be really a kind of protecting them from worsening of the disease, so one is the penicillin prophylaxis and two if they have pharyngitis you use available amoxicillin still works, Pen V still works, Amoxiclave of course if they can afford and Ampiclox is still there, these are all cheaper drugs that the patients can be able to get them from the main hospital

Interviewer: Ok...so what's your understanding of the long term prognosis of RHD?

Respondent: So the long term prognosis, I can say it is good, if the patient has the valve replaced if it is stenosis or moderate severe regurgitation if it is replaced, the patient's life expectancy I know the evidence in Aortic valve but I believe it becomes similar to the people of the peer age like the same age in the general population, but if that is not done, then they will be worsening of the disease and recurring hospitalizations, then complications then most likely they get cardio-renal syndrome and they might die.

Interviewer: Okay, so let's recall, (clears throat) let's talk about your encounter with these RHD patients, do you remember the last RHD patient you saw? Just of recent?

Respondent: Anywhere?, (Laughs), I just saw this two hours ago, I have a lady who is now waiting for me at the echo her she came with features of acute rheumatic fever and on auscultation she already has mitral regurgitation murmur.so

Interviewer: so.... how old is that one

Respondent: she is 14years.

Interviewer: 14 years, is she a female, is she in school?

Respondent: she is not at school because for the past three years she gets this recurrence of joint pains, migratory, she cannot get out of bed, then the next time she is fine, then she again gets it with sore throat so for the past three years she is not at school because of that, I just met her today.

Interviewer: Okay, You just met her today...So you said she is presenting with signs of rheumatic fever, she has a murmur on auscultation, how else is she presenting?

Respondent: mmh, She didn't have fever, objectively, subjectively yah she said she had fever but her temperature was normal she came with issues of joint pain which is migratory and she tried to demonstrate for me when the pain comes what happens, how severe the pain is with sometimes joints swelling and now she feels tired when she climbs a hill and she feels her heart is beating abnormally very high, she is aware of her heart beat, so that is kind of what really drove me to that, am still waiting for her blood test, then I am going to do her echo then I can be able to know exactly to what extent what she is having, so in daily practice I think it can't miss in a week for you to get two or three new cases of rheumatic heart disease, that's how common it is, yah.

Interviewer: okay... and are these patients aware of the link between sore throat acute rheumatic fever and rheumatic heart disease?

Respondent: They are not, they are not at all, most of the patients I meet, they don't have a clue of how this happens

Interviewer: Okay, why do you think so?

Respondent: its mainly awareness problems, these are people who have been into local clinics for treatment of a joint pain or a sore throat or they self medicate themselves with '*double colour*', that's what they say, that must be Ampicilin or Ampiclox or something like that, so there is lack of awareness still despite much work being done about rheumatic heart disease, it's still there is lack of awareness, it's not enough, so most of the people still they don't know, at all, yah.

Interviewer: So apart from this child you have said, you have seen actually a few hours ago, what are other sorts of symptoms other patients describe to you?

Respondent: It's so rare that patients present like this little girl or this young lady I have just seen, an adolescent, most of them really present with heart failure then during the work up is when you will find that the causes of the heart failure and the underlying etiology is actually rheumatic heart disease, or when other patients start to have syncope especially when they have moderate to severe aortic stenosis then that is when you tend to know or they have severe mitral stenosis they've started coughing at night, they cannot sleep, they get tired easily, that's the time they come and seek for help, but as we know that rheumatic heart disease, it takes time for you to develop the full blown out features in the heart, so some people are asymptomatic and they are there in the community and they don't know, so awareness is our biggest problem.

Interviewer: So are these patients good at follow up or adherence to their medications?

Respondent: Aaaaah, to tell you the truth patients in the rheumatic heart disease clinic, they can even teach you about rheumatic heart disease because they are like ambassadors, I call them ambassadors, they are the very people who can go and talk if somebody has a similar condition, they can be able to help them, refer them or channel them to seek for help because they have stories to tell to people and how their problems have been diagnosed and how they are now living better quality of life than before and most testimonies are from patients who got surgeries, valve replacement, they are really the voice because they have been for recurrent hospitalization, they have been in and out hospitals, they have been on multiple drugs but when

they had their surgery, they are now better, they are fine and they have like a testimony to tell those who doesn't know about it, they are more like ambassadors so they are more adhering to their medication they know all the benefits of each drug they are taking, and they know importantly the benefits of not missing their penicillin prophylaxis so for me these are the real people who can educate those who are down in their communities because not everybody has a radio if it's a radio talk show, not everybody has a TV set in the village but this normal talk, this discussion you meet and you talk is the better way to reach those who are really in remote areas to understand about rheumatic heart disease.

Interviewer: So these patients actually, you have said they are good at follow ups and adherence to their medications, so haven't you met some who have actually not adhered to their drugs and maybe have not come to follow up and they are stating some reasons why?

Respondent: yah there are few who are lost to follow up, we have two who have completely lost to follow up, I think one has travelled to Congo or something like that, and there are few that we see then, maybe after 3, 4 months, they don't respect their clinic days and the only time we meet them is when they are admitted in hospital for acute heart failure, and looking into that knowing the importance of taking their drugs, you find them getting more adhering to their medication and following up their appointments

Interviewer: So before that, when you meet them like after three months, what are some of the reasons they give, for actually not coming at the right time for following ups

Respondent: You know patients come from very far, not all of them are within Mbarara municipality others are coming as far as Kisoro, Kasese very long distance to come to the clinic, so money is the issue, financial support so most of them they don't have, if they don't have enough support from the family then they cannot follow their visits, they will say, I will try to look for money in order to come back to my visit or the money I have I better buy medicine with it, then if I get money, I will come and see the doctor and the other good thing also, the RHD nurse always is in contact with all the patients all of them if they have any symptom they call her first then she will advise them either to come to the clinic or to go to the nearby health unit or a hospital but financial constraint is the problem and aah some of the patients has issues with getting medication also prescribed for them, and aah with that sometimes they feel like not coming to the hospital because the little money you have I better get with it medication than coming to the hospital and that explains why most of the patients present late in the hospital or in failure because sometimes there is either the distance which is really very far to

come and seek specialized service or sometimes it's just the financial constraint that has not enabled them to come.

Interviewer: Okay, so most of them they actually state the financial constraint, you as a physician; do you think there are other things that probably stop them, from coming to get care apart from finances?

Respondent: There are few patients, aah not mostly, very few and rare cases maybe once or twice is a family issues if there is no like luck of family support is one of the thing you will find maybe is a young woman of 25 or 30 with severe rheumatic heart disease and has a child and the husband she has to take care of her family, now that becomes also a problem if the husband is not supportive and to seek care, yah those are some of rare instances, yah but mostly its financial.

Interviewer: Ok...so we are going to look at the local health system barriers now, am going to mention here some pieces you will tell me which ones work for you when you are trying to give care and actually which ones do not work for you, so let us look at administration and leadership at the district, administration in the hospital and leadership at the district, does it work for you when you are giving care to these patients?

Respondent: (breathes deeply) you know that the administration and the local government at the district have unit, this aaaah they call us, what do they call us? Health care delivery so for me who is really down, at the service down, let me say, I remember interviewing them for the same purpose (Laughs) yah, there is something called needs assessment if you know about it in rheumatic heart disease, we did the same interviews the DHOs and how do you call, the district amm...?

Interviewer: health educator?

Respondent: The health educators, you know somebody higher than that.... aaaah, anyway the CAO, yah the CAO and everybody, there is willingness and there is lack of knowledge because this is totally a preventable disease and if I have to look at a point of your public health, this can be eradicated, yah...Alright, other countries maybe who have done it and we can do it too but we have barriers which are really multi- sectorial at different levels like now the administrative they have willingness to do that maybe what is constraining them from providing, let's say penicillin at all...Benzathine penicillin at all levels, maybe it is the budget,

maybe their budget is limited now for that I cannot intervene much but there is willingness from them to help promote services for rheumatic heart disease to go on, yah.

Interviewer: Okay, how about the funding for health care system in general, does it work for you?

Respondent: That budget has never reached the target, and aaaah if the budget should focus more in health than other sectors that I don't want to mention, I think it would be better, like in Mbarara maybe the budget which is allocated to Mbarara, maybe it is the budget which was used some several years ago yet the population is growing, you know the more the population grows and if your supplies are fixed then you cannot be able to give services for the rest of the people who might come, so that's another thing that if the government will allocate better budgets for the health system I think it cannot help for service delivery.

Interviewer: Okay, that was in general, how about the funding for RHD in particular in this hospital how is it?

Respondent: The hospital.... funding for RHD has been through a grant, that's how it was established here. The Medtronic funding ended, 2017, then we had an extension for one more year of 2018 to follow up our patients, but from 2018 December up to now it is basically our willingness as physicians to take care of our Rheumatic heart disease patients we don't want to lose them, we kept the clinic running and the patients peer support group they also kept on encouraging each other to be in the clinic and try to raise their own funds to come to the appointments without fail

Interviewer: Okay, so are you being paid to do that, do you have the drugs do you have whatever it takes?

Respondent: No, so I am not getting any stipend for following up rheumatic heart disease patients or clinic, the funding ended way back, so this is good will, I can say so, and the drugs of course the drugs that enter the hospital is really through what...? one channel let me say it's a channel drug supply. Mmmh Penicillin has been around that's a good thing although it has been out of stock sometime around last year but now it's available so when it comes for prophylaxis I know my patients will get that, those who come with volume overload diuretics are available but now going for some other drugs like those which are for atrial fibrillation or things like that who might need anti coagulation they have to buy, those who have mechanical valves, those who had theirs from Salam centre they have drugs but those who got it on their

own ways or through some good Samaritans that help them to get it done, then they have to buy.

Interviewer: How about anti-heart failure drugs?

Respondent: Anti-heart failure drugs, what do we have the supply is really fluctuating, sometimes it is there, sometimes it is not, yah.

Interviewer: Ok...so you have already talked about drugs that one, we shall actually jump it, the medication, how about the health care workers, the numbers and the qualification

Respondent: For rheumatic heart disease?

Interviewer: Yes, is it working for you, do you have the numbers of the health workers to take care of these patients; do you have the right qualifications?

Respondent: not really because, we have only one trained Nurse for rheumatic heart disease and she has been around for the past five, six, seven years and she understood a lot about rheumatic heart disease more than any other nurse at her level.

Interviewer: Is one person enough?

Respondent: it's not enough, but now that comes back to funding who will allocate a nurse to rheumatic heart disease without training, one is training which we believe Heart institute will not let us down if there is a human resource and the human resource officer here in Mbarara they are not currently employing so it's so difficult using the limited human resource that we have to stretch them over other departments that becomes a problem but if we can get more than one, that would have been better.

Interviewer: Okay, how about the waiting time for these patients, how is it?

Respondent: waiting time, we have tried to improve that, so we used to have only one cardiology clinic which sees everybody except the paediatrics with that the waiting time was very long then we created our own rheumatic heart disease clinic because we believed that these patients, these are young people they need more time to understand exactly what they have and the treatment how it works and what are the potential side effects the young people you need to talk to them about contraceptives and so many other so we thought these are patients that needed more time than the usual patients we see we created for them a clinic to reduce waiting time, to create doctors- patients time this is not about just refilling drugs, that is a lot to do with that, yah so their waiting time is really not that long, I believe, yah.

Interviewer: Okay now, okay I can see, alright so I can see we are beating time, so let's try to actually wind up, and how about the health information system and the medical record system for the patients, is it working for you? Medical record systems for examples do you have the registers for ARF and the rheumatic heart disease patients?

Respondent: Yes, we have, we have files so our nurse does a lot since she is one, so she does good record keeping of all our registered rheumatic heart disease patients because there are people who are not registered we have more files for them which we do the follow ups and in case if they are lost we can follow them up with their address and their contacts and we keep records of those who are new and the old ones, we do that.

Interviewer: Okay, that is or out patients, how about the in patients?

Respondent: In patients record is for every patient who is admitted, of course the place of diagnosis will be rheumatic heart disease, yah.

Interviewer: So there are no separate records for the inpatients.

Respondent: No, no there is no separate record

Interviewer: And aaah, do you have the guidelines and protocol for rheumatic heart disease care?

Respondent: Yes there is the old one although now according to the new published data we have also the WHO has re-defined rheumatic heart disease so the old one yes we have and based on that is how we screen our patients, yah.

Interviewer: So you said these pieces we are going to actually go through them again, you said the administration is fair, is not working

Respondent: They are willing, the willingness is there.

Interviewer: but for now it's...

Respondent: mmmmh mmmh

Interviewer: It's not working. Funding for health care in general for rheumatic heart disease patients is not working

Respondent: it's not, yeah.

Interviewer: Health care workers, that is numbers qualifications is not working?

Respondent: Specifically for rheumatic heart disease, no we only have one nurse.

Interviewer: Okay, and...Medications you talked about

Respondent: The supply is really up and down sometimes its available, sometimes it's not

Interviewer: So it is fifty fifty

Respondent: yah, its fluctuating

Interviewer: Okay and the medical records is working for you?

Respondent: The record for the out patients of rheumatic heart disease, yes but the inpatient we don't have a separate record

Interviewer: Do you think it's important to have an in-patient separate record?

Respondent: I am thinking, having the outpatient is good because that is how we track them and the good thing is every patient admitted to rheumatic heart disease is discharged through rheumatic heart disease clinic so that we capture even those who are new, those who have just come for admission, aaah I am not sure whether we have missed any the system has been really good through the SHOs they always channel rheumatic heart disease to their specific care upon discharge, has been working well, but if it for record keeping specifically inpatients, I don't know whether it can make any difference, am not sure.

Interviewer; Okay, and the guidelines are there, guidelines of protocols you said it's working for you?

Respondent: Yah it's there.

Interviewer: Okay, good, so let's go to the last set of questions, this is the last one, the last one; generally do you think the patients get the care they need, for rheumatic heart disease

Respondent: In the rheumatic heart disease clinic is a yes,

Interviewer: And do you have any patient safety concerns for example, do you have any preventable deaths in the hospital that are happening?

Respondent: Because of rheumatic heart disease?

Interviewer: mmh

Respondent: Preventable deaths, none that I can think of you know most of our patients who come in failure they are really end stage heart disease and in that stage sometimes what we can do is really limited so the best strategy is actually prevention of rheumatic heart disease

Interviewer: Okay, and do you think there are many patients there in the community dying without actually presenting to the hospital and why?

Respondent: Yes that's a big yes, still awareness is the big problem it's still long distance to access care why am saying is a big yes is one time I visited Kisizi hospital in Rukungiri and each day I could go there I could find people newly diagnosed with rheumatic heart disease and there was a young lady coming to deliver but unfortunately already had a stroke so I managed to find three or four with multiple intra cardiac trauma seated , that gives me a crew that there are many more people like that in the community it's just because they are not aware, they are there and maybe even dying and people don't know, yah.

Interviewer: Okay, so in your own opinion, what are one or two most important things as we are winding up, ministry of health can do to improve on the outcomes of these patients

Respondent: One is availability of the drugs for these patients, is the most important for me, and if the ministry can put rheumatic heart disease at the top of their agenda and raise the awareness at all levels in the country, that will increase peoples as diagnosing them earlier on and preventing death. if they can put it at the top of their agenda, that will really be great we will not be seeing people who are really dying at a very late stage and we can't do much to them, then if we can have, that might be ministry level or not ministry level, wide spread, like you do screening especially to specific neglected population, let me put it that way, you have the street kids, you have those in the refugees camps you know, it's so important because they are also at a high risk of developing rheumatic heart disease and if to simplify I know people started the nurse hand held, ultra sound, just with the simplest guidelines to check possibility, probable a rheumatic heart disease if that government can also take it up and the nurses down in health centres 2,3 are able to screen for rheumatic heart disease I think we can be able to reach out, we can be able to prevent others, and diagnose early and prevent death.

Interviewer: Anything else, do you have any other thing you want to add before we close.

Respondent: What I can add is really for these people in the lower health unit if there is a simplified diagnostic criteria or approach that would really help them to be able to diagnose and refer early, alright.

Interviewer: Okay, thank you so much for allowing to participate.

Respondent: Thank you too.

Participant ID	HW 012
Age	■
Date	22nd /Nov/2019
Venue	Echo-room-Pediatric-ward-Mbarara Regional Referral Hospital
Interviewer	

Interviewer: Today is the 22th November 2019, and we are here in Echo room, paediatric ward- Mbarara Regional Referral Hospital to meet a Paediatric cardiologist, you are welcome doctor.

Respondent: Thank you.

Interviewer: So this study like I told you is to determine how to provide care for rheumatic heart disease patients and there are no wrong or right answers please be frank and share your opinions with us and the data we gather here is going to be very confidential we shall not link it to your identity and this is participant WH012, so doctor please tell me a bit about yourself, your age, don't say the name, how old

Respondent: I am ■ years old

Interviewer: Okay, and qualification, and where you trained from?

Respondent: ■
■

Interviewer: Okay, how long ago was that, how long did you qualify ■
■

Respondent: ■,

Interviewer: And how long have you been working in Mbarara regional referral hospital ■
■

Respondent: ■
■

Interviewer: Okay, so let's look at the demographics of the patients we seek here, in terms of age and the common illnesses they present with.

Respondent: aaah generally here in the ward under paediatric we see children who are below 12 years that is our cut off, so most of the children I see are bound to be below 12 years and you know they have a specific demographic.

Interviewer: common illnesses that you see in them that cut across from neonates to....

Respondent: Of course there is the issue that they come with congenital heart disease and the acquired diseases and the patterns don't change that much from what is being written most of them commonly are going to have VSDs and tetralogy of fallot being the commonest cyanotic disease and the commonest acquired heart disease being Rheumatic heart disease.

Interviewer: Ok...apart from heart diseases what are other common illnesses generally that are here on the ward?

Respondent: On the ward? On the ward there are many things, the biggest problem we have now we have neonatal diseases they contribute almost like 30 percent of the admission, then the other 30 percent comes from malnutrition then the other 40 percent cuts across in infectious diseases we have pneumonias they come in with meningitis, yah.

Interviewer: So tell me a bit about your training on rheumatic heart disease in school for example, did you have any training in school about rheumatic heart disease?

Respondent: In school, yah we used to have lectures about rheumatic heart disease

Interviewer: Post graduate?

Respondent: Yah we did a whole module on cardiology and we covered rheumatic heart disease under that.

Interviewer: So apart from the school time, have you had any specific training on rheumatic heart disease that is after graduation?

Respondent: what do you mean by specific training?

Interviewer: Let it be a workshop specifically about rheumatic heart disease

Respondent: Yah, of course in fellowships we had to study about rheumatic heart disease but there was also a time we had to it was like a workshop I think I have had like two when we are going to do school screenings so you start with a refresher course on what is expected.

Interviewer: When was that, and where and by who?

Respondent: aaah I don't know whether I will remember the specifics all I know is we did the school training, I think like 2016, 2017 from Mbarara, yes and then we did one again in Kampala, yah the one I remember specifically was here, I think it was, what's her name, and Dr. and We did a lot, and mostly we have had like two, actually here in Mbarara we had two because we did the first school training and then we did again.

Interviewer: Ok...so now, how many patients of RHD do you see for example per day or per week or on a monthly basis roughly.

Respondent: there are two things that come in that, one, is that we have those that are coming back for review and those who have seen as new patients so for new patients we see almost on average like two newly diagnosed patients per week

Interviewer: okay, are those in patients or outpatients?

Respondent: They can be both, if they are coming for the very first time we do prior diagnosis and all that, the diagnosis for rheumatic heart disease and those who come for follow up

Interviewer: In a month, those who come for follow up in a month roughly, how many do you see?

Respondent: Maybe like ten

Interviewer: Okay, now I am interested in knowing what you were taught about rheumatic heart disease, for example in those workshops you talk about what do you understand is the cause of rheumatic heart disease?

Respondent: well, I mean rheumatic heart disease is more of an auto immune disease really, it's a sequelae of auto immune disease that you get your valves damaged following Acute Rheumatic fever which is an auto immune, it's a reaction of your body to group A streptococcal bacteria (door open)

Interviewer: Okay, are you aware of the link between a sore throat and rheumatic heart disease, what about it?

Respondent: Yah for you to get rheumatic heart disease, there must be a preceding sore throat which results into acute rheumatic fever and the recurrence of those sore throats and rheumatic fever which exposes you to rheumatic heart disease.

Interviewer: And what were you taught can be done to prevent rheumatic heart disease?

Respondent: One of course is the eradication of the strep which maybe, people have tried vaccines and all that, but also treating the sore throats and also once you get acute rheumatic fever, you prevent other recurrent acute rheumatic fever episodes.

Interviewer: Okay, how about the treatment options, what were you taught treatment options for RHD.

Respondent: The options, it depends I guess, one, if the patient is in heart failure you want to do the symptomatic management, managing heart failure then the definitive management depends on how sick the valves are whether they need to be replaced, whether you have to do a valve replacement, a valve repair, yeah.

Interviewer: So you are saying you manage them by surgery, that's what you are saying?

Respondent: yes, definitive management.

Interviewer: Okay and what do you understand about the long term prognosis of RHD

Respondent: From books or from...?

Interviewer: From your own experience.

Respondent: I think rheumatic heart disease has a very poor prognosis, that's what I have come across especially when there is no intervention, in our setting it is not very easy to come by the definitive management we all do give medicine for heart failure but we don't know what's causing it and if there are challenges in themselves, patients coming back for review, coming back for, getting their medications and all that, so most of the children actually die, that is one thing that I have noted, in this last month, we lost two children.

Interviewer: Oh, sad have you had those that you have treated and they have actually regressed?

Respondent: I hope one, okay, this one was, others regress and the disease becomes mild and they yah, and they just stay on Benzathine and we take them off the anti-failure medicine medicine, those ones actually we have seen them. There is one who came with severe mitral regurgitation we were with them for almost like a year and a half and the symptoms regressed completely and they reached a point where they had trivial MR, we stopped all the anti-failure medicine and we just see them, they continued their injection, and we see them like once in a year because they come from far so we just tell them take your injection and they can only afford to come like every after 6 months or a year. They come from Fort, that side.

Interviewer: Okay, so now let's talk about your encounter with these RHD patients, do you remember the very last patient you saw with RHD, the very current one, by age, how they presented, were they in school?

Respondent: Okay the last patient I saw, the most recent I saw this week, and this is when?

Interviewer: This is Friday

Respondent: This is Friday? Okay (Laughs) I saw them I think on Tuesday this week, yah six year old, first time presentation and the complaint were easy fatigability, cough that was persistent and the history of body swelling and they had had their symptoms for about four months. The child was supposed to be in school middle class but the child wasn't attending school actually they had had to bring their exams to their home because the child couldn't walk to school because of getting tired.

Interviewer: Okay, so In your own opinion do you think these patients are aware of the link between sore throat, acute rheumatic fever and rheumatic disease?

Respondent: No, they are not.

Interviewer: Why do you think they are not?

Respondent: I don't know, they just don't know the information, when they come the first time, they don't have that information, so this particular one was coming from Ibanda-Ishongororo, it's on the way to Ibanda, didn't have an idea at all that there was anything related to sore throat, had been brought by a father, so, usually fathers are not good at giving history, was not even aware the child has ever got sore throat or has ever had joint pains or even fevers, yah most of them don't have an idea at all, even those that you see when they have acute rheumatic fever and they are educated, university graduates, it has never occurred to them that sore throat can lead to rheumatic heart disease.

Interviewer: Okay, now, you said they describe symptoms, for this current one you said cough that had persisted, body swelling easy fatigability, how do others present?

Respondent: The commonest presentation actually is body swelling, it's the commonest, and then these other things of cough, they stay home because they come and tell you, we been giving everything, they have given Amoxil, we have given antibiotics the cough is not going away but when the child starts swelling, that's when they start actually thinking about;

swelling, difficulty in breathing and easy fatigability but the commonest reason they come in here for check-up is because the child has started swelling.

Interviewer: Okay, and are they good at follow up and adherence with their medicines?

Respondent: No, they are not.

Interviewer: Why?

Respondent: They are not

Interviewer: what are the sorts of barriers they commonly state to getting care?

Respondent: The radius we serve as a hospital is really vast so and because it's not like all of the patients we see come from Mbarara, they come from as far as Kamwenge, Kanungu, Kabale, think of all those far places, Kisoro whereby this is you have a child who is not a baby that the mother is going to carry, so transport becomes the first barrier, that is you need to pay two seats, so two seats if I use an example of someone coming from Kisoro to here, two seats, one journey is like 30,000 assuming that you are from the town, not including the journey where you are coming from, your home, and now going back is another 30000, 15000, 15000 that makes it 60000, its not common that a parent by the way, these peasant parents can afford a minimum of 60,000 every month, it becomes very difficult because remember, once you see them they have to do their monthly Benzathine and sometimes you are not very sure whether the health centres they have are going to be able to do that, it becomes very difficult.

Two, they come here and you see them and you write medication and they go to the pharmacy and the medicine not there, so they have to buy this medicine and I can't control I don't even know the price I think maybe I need to find out but each pharmacy sells medicines at different price. So you don't know how much money they charge them there, once you leave hospital and go to private pharmacies, so sometimes patients look at medicines and decide, this is what I am going to buy, I don't know what determines their choice of choosing, you write medicines and after they say I am going to choose, some will choose the cheapest and that's what they will be taking, instead of being maybe they are supposed to be on an ACE inhibitor they are supposed to be on a diuretic and they choose one that is cheaper and they only take that so that so that next time you see them, they come back again in heart failure, you ask them what's happening , and they tell you, I have not had medicine in two weeks or when we left here, we didn't have money we first went home, thou for those who were admitted, so you leave

inpatient care and you go home without any outpatient medication and within two weeks you are back, so what do you expect.

Interviewer: Okay, so they are not good at follow up and adherence because of money for transport the distance and medication sometimes are costly so you what do you perceive is the barrier that is stopping them from getting the care that they want

Respondent: I think I agree with them that the distance is so, it's difficult for them, that is what I think, yah.

Interviewer: Any other you are thinking, apart from those you have just said

Respondent: I don't know whether I am not thinking even now but (laughs) because I see those patients myself, I don't think it has to do with these other barriers of health workers because they know where to come you understand, they have my phone, sometimes I want to call you and ask you....."that see my patient and my child is swelling again", but you cannot treat a swollen child on phone, it's not like there is an issue with a health worker here, it's like RHD patients have been one of those that have been protected I guess from the different studies that have been on, they had access to medical people but when it comes to having to deal with money issues, they actually don't have.

Interviewer: Okay, so let's look at the local healthy system barriers, I am going to mention some pieces and you tell me those that work for you and those that do not work for you. We are going to start with the administration here at the hospital and the leadership at the district, does it support you to do your work?

Respondent: (Laughs) I don't know, I don't think so because, I mean, this whole clinic as it were, its running and the equipment, didn't come from the administration, didn't come from the hospital, no. I am not even sure if the hospital is necessarily, they are aware that we have a cardiology service really but they are not interested in how it runs.

Interviewer: Ooh, why do you think they are not interested?

Respondent: And they give us reasons sometimes before that, you see this is a regional referral they don't expect to have cardiac services so you can't like ask maybe that the machine is down I need money to repair it, they will tell you we are not aware, such services it's not in our protocol that we are supposed to have these things, so it becomes a bit difficult so whatever you do, you have to do it under the department and this is time of the complex department, we

have university, we have hospital so finding the border line where this cuts into the other is a grey area which I myself never want to explore because you just get, you're just disturbed for no particular reason. But for inpatients, they have drugs, some drugs, they have the IV Lasix, they have the IV Digoxin then sometimes they have Captopril but I don't know how much on what they use to decide to procure but they know the patients are there but that's all I think, that's as far as it goes in their involvement.

Interviewer: So talking about medications, particularly Benzathine penicillin, is it available

Respondent: it is, Benzathine is available.

Interviewer: Anti- coagulation drugs?

Respondent: aaah No

Interviewer: Anti failure drugs?

Respondent: Some

Interviewer: Okay, and how about the diagnostics particularly echocardiogram is it available?

Respondent: We have the Echo.

Interviewer: Okay, do the patients meet it at a cost?

Respondent: No, here in paediatrics we do it for free entirely because the machine can as a grant, I mean some people gave us a choice of what we needed at the time and we asked for the machine so some of the terms and conditions are that patients are not supposed to pay for that machine so we do the Echo for free.

Interviewer: Wow, how about the funding for health care in general and RHD in particular

Respondent: I don't know about the funding, eeh I don't know, I have no idea about the hospital funds and how they allocate their money, no, I have no idea

Interviewer: How about the health care workers, particularly the numbers and the qualifications they have to do the job here as far as rheumatic heart disease is concerned, do you have enough numbers of the health workers, do you think you are fine with that?

Respondent: No, we don't have enough numbers like I said this clinic is not necessarily should I say known, using the word in quotes by the hospital, so we do not have a nurse and me who runs the clinic, I am not under the hospital, I am running this probably out my own, I don't

know, passion because I am under the university so the man power that I tend to use are the post graduate students who you would say, you assign a post graduate student for their learning purposes so they have to rotate in the cardiac clinic see patients under your guidance and all that but we don't have anything under the ministry in plans of that, no.

Interviewer: And how about the waiting time for our patients, do you think you are okay with that?

Respondent: The waiting time is fine.

Interviewer: Okay, the quality of care you give to them, are you fine with it?

Respondent: it's me who gives, I won't be a judge of myself (laughs) it might be difficult but I think I am comfortable with what we give, I mean I may not be able to provide you with the medicine but if I am able to explain to you what the disease process is, what it ought to be doing, how to take the medication and all that, I think on my part as a health worker maybe that's the best I can do, when it comes to you finding the medication I feel that that's not my problem really, when it comes to you going for surgery, the best I can do is to refer you, so the issue of 'do I have the money? I don't have the money,' that becomes a different story yeah, but for these patients those we see, we manage to get some worked on, we send them to, those we really we assess and they need surgery like urgently, we send them to Mulago, we get touch with their representatives of Salaam centre they get surgery, some have gone to different places, to the US, so at least the best we can do is to tell you, the magnitude of your problem and then we tell you what the options are, we give you an estimate of what they are going to cost and then the next step is you deciding how I am I going to find the money, yah.

Interviewer: Okay so now how about the health information let's talk about the medical record system, does it work for you here for both inpatients and out patients

Respondent: The medical recordings are a bit difficult especially if you are the doctor, you are the nurse, you are the one taking records, it's just difficult.

Interviewer: Do we have specific registers for RHD patients here or ARF patients?

Respondent: Not in that sense, I mean everything is, under me, that if I see you, I type I do your echo I do your report but the ones I may record are the ones whom I think, the RHD we record I personally record their names and their addresses because the reason I want to be able to have a list in case people of Salaam centre come, they don't come here but they come to

Mulago and ask us where are many patients who need so if I have that list it makes it easier for me to just pick out names because you will get their name, their address the diagnosis and their phone contact and where they come from, like district of origin just like that so when such a thing comes I just get the numbers off but otherwise that other information is based on the Echo report that I have, which I keep in my computer.

Interviewer: Okay, let's talk about the Salaam centre I have heard of it from you many times, what's this centre?

Respondent: Salaam centre is in Sudan, and it gives free surgery for RHD to patients.

Interviewer: Oh okay, wow, from Uganda only?

Respondent: I think they do other countries but I think I read they do from even other countries in Africa, yah.

Interviewer: So that surgery, where is it done when they come for these patients?

Respondent: They come for the patients, and select them and the surgery is done in Sudan.

Interviewer: In Sudan, Okay and, aaah so let me ask you again about these records, so If I came here to look for a certain patient for example who presented in rheumatic heart disease about three years ago, how can I easily trace that patient.

Respondent: It's difficult but if he has been coming sometimes you know the patient but the best I can do is usually to trace like their serial Echos, because we do not one; all the records that we write for the patients information, the patient goes with them because we do not have a stationery where they are going write, so the patient buys their own book and we write there everything in that book every time they come, yah.

Interviewer: So there are no records here, that is it, how about the guidelines and protocols for RHD care, is that piece working for you, do you have all that it takes as far the guidelines are concerned to give care to RHD patients?

Respondent: I remember the guidelines I don't have them pinned on a wall, but it's like something I mean I have studied and it's what I follow.

Interviewer: Alright, so we talked of these pieces we are just going to go throw them again quickly and then we see the pieces that work for you, Administration you said it's not working, right?

Respondent: it's not.

Interviewer: Funding for health care and RHD in general?

Respondent: It's not working.

Interviewer: Health care workers as far as the qualifications and the numbers?

Respondent: it's not working, but we don't have the numbers so we cannot discuss their qualifications.

Interviewer: Okay, and then the medical records, that piece u said it's not working, and then the guidelines you said that one is working for you.

Respondent: The guidelines are okay.

Interviewer: Okay, then let's go on the last piece of questions now, generally do you think the patients get the care they need especially surgery?

Respondent: (Laughs) of course..... this hospital doesn't do heart surgery, No, it doesn't

Interviewer: Why do you think it doesn't?

Respondent: I mean it takes....,I mean how many cardio thoracic surgeons are there in the country to start with, and all of them are in heart institute, so here there are other things, I mean if you, heart surgery is something especially valve surgery, one it's expensive, you need to find the valve, you need to have an ICU that is going to work for you or ICU I don't know, that's a different story maybe it's a story for some other time but it's not like it has all these gadgets, they are also not probably stuffed, they do not have, we do not have bypass machines in the theatre, theatres are not prepared to do surgery here in Mbarara, so it's not something that is done here, the only place that does surgery, cardiac surgery is Uganda Heart Institute

Interviewer: Okay, so they go to Uganda Heart Institute they are operated on,

Respondent: If they pay, it's not free, the Uganda heart institute is not free, they have to pay, yah. And you can't tell a peasant who has never held a million shillings in their hand that now you need to pay 19millions for surgery, it's not easy, yah and children are a bit unlucky they don't a lot of that support, they don't own their own health care, I don't know how adults do it maybe adults do go for surgery but children, if somebody has to get into their pockets to pay for you it's not easier for them so they don't want to know because they don't feel your pain.

Interviewer: Alright and do you have any patients safety and quality of care concerns for example, have you had any preventable deaths here in the clinic?

Respondent: there are concerns that I have had actually I have been with Benzathine, we have had two deaths following Benzathine not because it's anaphylaxis because these are the children who have been taking Benzathine for more than so many years but they have given them Benzathine and they just rested.

Interviewer: Okay, in your own opinion that do you think you would have done to prevent the death.

Respondent I have never understood why they died but it's, I think from literature what I have read they talk about neurogenic shock, they talk about the pain, the parasympathetic response and maybe it explains why, yah.

Interviewer: So talking about those two cases did you try to do some resuscitation or CRP and they didn't come up.

Respondent: Yah, they didn't come up, one was an OPD, was not a child, he was 19 but he was still under our care any way because he was a small 19 years, that was on OPD, he walked from home came in for his routine treatment and Benzathine because he was from Mbarara radius and usually he came for his Benzathine every month, the injection was given by a nurse who is trained who had be giving him the same injection and he just collapsed. Tried resuscitation, he didn't make it. The second one died from the ward here he had been admitted but maybe had many issues and had surgery that was the most interesting thing, and had surgery but came in with issues that are not understandable but anyway we stabilized him, he was on the ward and was just receiving his treatment for heart failure, had come in with anaemia but I had had him on the ward for like a week, so his time for Benzathine found him here, so they give him Benzathine, he just died.

Interviewer: Okay, that was sad, do you think there are many people there in the community dying without actually presenting here at the hospital?

Respondent: Yah, there are many because there are those who come in and die in the hospital, they come in with heart failure and die, that means there are many who do not arrive here because they do not understand what the disease process is. So they have been everywhere and done everything, I think the community have a lot.

Interviewer: So putting into consideration all that you have said, so in your own opinion, what do you think are one or two most important things ministry of health can do to improve the outcome of the patients?

Respondent: The ministry needs to create awareness, really that these patients and their parents need to know that the disease is out there, it's not something that is in our mind, it's not there that is one two, there is need to make it easy for patients to access medication, patients can be stable because not all of them come in when they are so sick but because they have been getting their medication, they get worse during hospitalisation, so if say they could provide the medicine for these patients. Then the other issue I don't know probably it's not, I don't think it's that feasible would be for surgical options even if somebody needs a valve they should be able to get it, because without a valve, all these things we are doing we are just, maybe prolonging life but not prolonging life that is of good quality.

Interviewer: Okay, talking about this clinic particularly you said it's not here because of the hospital administration and ministry of health, so supposing you left this university, probably you could go to another university in another world maybe not in this country, what do you think would happen to the clinic?

Respondent: It would stop.

Interviewer: Do you think there is anything that can be done to actually maintain this clinic running? Any suggestions?

Respondent: The suggestion would be to have somebody trained, to have more people trained that they can always come back, but it's,.. like I said it's not a clinic that is in structure so it becomes difficult especially if somebody is just doing extra work load without extra incentive like I said I run this clinic because it's something I want to do, but there is a possibility that I will no longer want to do it, I will get tired, so if I get tired, I don't know I will ever wake up and say, I no longer want to do cardiology, now I want to go into farming, currently there is nobody who can do that, because, one the training is very difficult, training for cardiology is your own initiative, you wake up and say I want to go and train. you don't have anybody paying for your training, I was lucky that I didn't have to pay for the fellowship, some people have to pay for the fellowship so unless you have somebody supporting to do that, it becomes difficult, the training is not here, you have to go to Kampala so if you have other commitments here it's not something many people are willing to do, so even for everyone that suggests that you need to go and do the training they will ask you, for those three years "how I am I supposed

to survive?”, I don’t have money, I won’t find a job that gives money, I have family, so the whole process of training becomes very difficult so unless somebody puts in efforts to train, either government or whatever it is ,so they train somebody that they have or ministry of health sends somebody to train who is attached to them, it can’t stay, I mean there are times when I am sick, the clinic closes because nobody is going to do the Echo, post graduates maybe be able to do drug refill and they may be able to say, identify that the child is in the heart failure and give heart failure medication but that's as far as they can go, yah.

Interviewer: Okay, Alright, so before we close do you have any other thing you would love to say to us?

Respondent: You as whom?

Interviewer: As acute rheumatic fever study team.

Respondent: I don’t know, I wonder acute rheumatic fever study team, when these things, your study ends, so what's going to happen, do you realise that, yes you have kind of maybe screened many patients, you are giving them review dates and all that, but when the study falls, where are all these patients going to go?

Interviewer: We hope to leave them here in your clinics.

Respondent: So, and that's where the challenge is going to come, you are going to leave many patients who do not have a really structured plan because you are working in a system where you have also come and must have realised the time you are here that you are there but the administration really doesn’t care, yah. They will not say maybe you should get somebody to train and understand what you are doing, or to get somebody to learn the ECG so that when you go maybe you leave the ECG behind or that V scan somebody can be able to use it, they are not, they are not really interested, that means that when you go, everything stops, and that burden that you have created, I think you are going to put a burden that you will not be able to deal with.

Interviewer: (Laughs) so doctor, do you think you can actually in your own capacities try to find out that maybe someone could be trained maybe?

Respondent: I don’t know the issue of training, like I said people do not want to get out of their comfort zone and you can’t get people out of here already they tell you, we have issues of under staffing we have what, so you have three nurses on the ward here, so you have three

nurses, you have 100 patients, so whom do you take off to take for training, okay you understand, so that thing that I just keep wondering and okay I think I was going to say it on record (Laughs), but like I said the way this clinic runs it's based on external funding the echo came from somewhere else, the ECG machine came from somewhere else, the paper came from somewhere else so we tend to depend so much on grants and good will and all that to sustain this, but I don't know how long it's going to sustain, there is time when this machines breaks down, you don't have the machine for like two weeks but then the hospital cannot pay for all that then you have to go and see the ones who gave you the machine tell them that the machine you gave us, died, and we have had this machine I think for six years. yes we have had this machine for six years, so just imagine someone gave you the machine for six years ago and you have to call them again and say by the way the machine broke down so we need money to take it for repair and they tell you, you know lets first go and do a run for you, how much money do you need to repair then you say maybe like we need 1000dollars, that is like 3.7million and you have to go and do a run in their country and collect money and send here. These are things that we need to own up ourselves, but this is a government hospital you cannot make patients pay maybe the owners of the machines don't want you to make patients pay, so it's just.. you just do what you can do, when that time comes and people part ways, I don't know probably will be, or we shall jump that huddle when it comes but the fact is that when I am on leave it closes until I come, yah

Interviewer: Alright doctor, thank you so much for your time, we appreciate.

Participant ID	HW 001 -Wakiso
Date	20 /Mar/2019

Interviewer: Today is the 20th of March and we are at UHI in the tea room, and we are seated with one of the health workers. Okay, then, um, so tell me about yourself; how old are you madam?

Respondent: I am ■ years old.

Interviewer: And what are your qualifications?

Respondent: I am a ■.

Interviewer: Okay. And then, um, where did you train from?

Respondent: I did my degree from ■.

Interviewer: Okay. Then how long ago did you qualify?

Respondent: I qualified in ■.

Interviewer: ■?

Respondent: ■ years now.

Interviewer: ■ years now. Okay, and then when you look at the RHD patients you've seen in the ■ years, can you just tell me about their demographics; who are the typical RHD patients you see? Are they boys, girls, women, men, are they married or not married? In a few words, how can you describe them?

Respondent: RHD, what I can say is that it's a condition that affects both age groups and both sex. It doesn't mean that it comes to one age group or sex; both of them can have it.

Interviewer: In particular, what's the dominant group that you are seeing? Are they children or not children?

Respondent: It's in both.

Interviewer: It's in both!

Respondent: Yes, but I can say it's more in female than male.

Interviewer: And when you look at the marital status, where do you say the main . . . is it the married or the . . .

Respondent: No, it's both.

Interviewer: Are they in school or not for the children?

Respondent: For the children, yeah; most of them come from school.

Interviewer: They come from school!

Respondent: Yes.

Interviewer: Thank you so much. And then, here in the . . . apart from RHD, which other conditions do you handle here?

Respondent: We handle all the heart patients.

Interviewer: All the heart patients?

Respondent: Yes.

Interviewer: Which common illnesses? What kind of heart illnesses . . .

Respondent: Hypertension, those who have come with heart failure, um, those who have come in with stroke, plus any other heart conditions.

Interviewer: Okay, and then if you look at the different categories like the stroke, which age groups do they lie in typically?

Respondent: So far like for the stroke, um right now, what I can say is that stroke does not vary it; it depends on what caused the stroke. It can be like in 20, 18 or 30, like that.

Interviewer: But most of them are?

Respondent: Beyond 25 years or age.

Interviewer: Okay, and heart failure?

Respondent: Heart failure, I can't say because all age groups are affected.

Interviewer: Okay. Thank you very much. Now tell me a little bit about your training in RHD; did you receive any specific training in school?

Respondent: Actually I can tell you no, no. Why? Um, maybe I have not gotten that chance of like our sponsors or PIs or those coordinators to take us for those further trainings. No! I personally, just go on by 'googling' to do my own research about the RHD and I find out more about it, but undergoing training, no!

Interviewer: How about in training; when you were in the nursing school did they give you any . . . did you handle the topic at any one . . .?

Respondent: Yeah, we handled that topic about rheumatic fever which ended up saying that it can go on with a complication of rheumatic heart disease, and they gave us like the cause, signs and symptoms and treatment for it.

Interviewer: Can you tell me a little but about the causes you remember?

Respondent: They told me that it is being caused by the streptococcus.

Interviewer: Okay. And then what are the symptoms you remember being told about RHD?

Respondent: The symptoms; these are the patients who can come in with joint pains, fevers and sometimes they came with edema of the lower limbs, chest pain, um heart palpitations and some can come in with sore throat.

Interviewer: Okay. Thank you very much. Now apart from that little training during school, after graduation, have you had any training whatsoever in RHD?

Respondent: Actually no. When I came here, when I was appointed to be a researcher nurse we had a one day session about rheumatic disease. They trained us about Benzathine injection, the criteria; how to know that this is a rheumatic heart patient.

Interviewer: So in your training they taught you about the treatment and how to identify an RHD patient?

Respondent: Yes.

Interviewer: And that was all in one training?

Respondent: What I remember is that it was one day.

Interviewer: Ever since then you haven't had any other training?

Respondent: No.

Interviewer: What do you have to say about that? Are there any training gaps that you can . . .?

Respondent: Yes; really this is a challenging condition where by um, you know when you be in it you find many challenges. So we need like a training about it, not the other one we had in school. You know they can teach you but not the detailed part, but when you come on ground you find so many things. Like, when I came here, back in my training, my nursing training, they told us about Benzathine; they told us we give 2.4, but now when I came here and we did that training, the one day session, they told us to give 1.2, the reason being that this treatment, but the other we were giving it like a shot, like start and that's all. So if at all you don't have that idea, you are going to miss everything. What I have also seen is that some of our doctors really get that challenge whereby they don't even know how to give the dosage, I can say that. When you to him or her and say, "please, change the dose to 1.2!" others are going on with the other training of 2.4. Yeah.

Interviewer: Any other challenge that you had, where you need more training?

Respondent: um, the challenge is that we need to maybe go to the counselling sessions because these patients who are sick and you have to counsel them emotionally because of the condition which is untreatable, so they are supposed to be with it for the rest of their lives. So you have to counsel them plus their family members so that they can support that patient to go on with the condition; he has to be with the condition for life. It's not an easy part or thing. It's not so easy to counsel the patient; he has come in normal with a slight chest pain and at the end of the day the ECHO scan comes back and its like, "your valves are sick; you are going to be on life time medication." To counsel that patient or person, you have to really have the knowledge of that counselling bit. So what we are missing out . . . the good thing is that where I was working before coming here, I did the PMTCT, so it gave me that knowledge and that gap to fit in my ideas here.

Interviewer: Okay. Does that mean that here in the institute the counseling bit has not been handled? People have not been trained as counselors?

Respondent: No.

Interviewer: Okay.

Respondent: Maybe someone will just come in.

Interviewer: okay, counselling. Which other area apart from the counseling?

Respondent: that's it.

Interviewer: Okay. So, with your work with RHD patients, any other area that you are not comfortable with or where you think you need more treatment?

Respondent: No.

Interviewer: you are comfortable you give treatment and . . . ?

Respondent: yeah.

Interviewer: Okay, thank you. Okay um, in a week, how many RHD patients do you see typically?

Respondent: [sighs] I can say they are more than ten.

Interviewer: In a week!

Respondent: In a week, and those are new patients

Interviewer: Each week?

Respondent: Each week, because in a day I can drop off like three to four patients in one day.

Interviewer: Okay. And then for those who are not new, the total number of the new and the old how many do you see in a week typically?

Respondent: Very many; they are very many. I can see about like 13. Let me say 15 to 20.

Interviewer: Okay, and then when you look at those RHD patients, do you have more out-patients or more in-patients?

Respondent: We have more out-patients than in-patients. They come in to be in-patients when they have got heart failures.

Interviewer: So you get more out-patients?

Respondent: Yeah.

Interviewer: Okay. And then, so are you aware of any link between a sore throat and RHD? Is there any association?

Respondent: A link?

Interviewer: Yes.

Respondent: Yes, because you cannot have RHD without having a sore throat. Why? A sore throat, that infection like I told you, that infection begins from the throat and then it goes on slowly by slowly damaging, then into the antibodies and then to your valves. But if it's being detected earlier when it's still a sore throat, then we call that Acute Rheumatic Fever and it's treatable, but if you jump that part and then it goes to the valves, that's when you have the RHD.

Interviewer: Okay. Thank you so much. And then um, so tell me about what you know about the treatment of RHD? How do you treat RHD?

Respondent: RHD, um, we treat it with an antibiotic called Benzathine Penicillin, the dosage depends on the age and the weight of that patient.

Interviewer: And then, how can someone prevent RHD? I know you hinted about it but let me get more.

Respondent: First and foremost, you have to make sure that at home your room is well ventilated, and if anyone has got a sore throat or a cough, treat it with antibiotics with a qualified person. Never to buy drugs from the drug shops because that's how our patients really die; they buy their drugs from drug shops and one day or two when the symptoms have subsided, you go off the medication and at the end of the day the infection goes on spreading and you get the infection.

Interviewer: Thank you so much. And then um, so we talked about the causes of RHD and you said it is mainly? I mean the cause of RHD.

Respondent: That streptococcus.

Interviewer: Okay. So what do you understand about the long term prognosis of RHD?

Respondent: [sighs] Long term prognosis! Um, what can I say? The prognosis is actually, I can't say poor or good. Why? We have had patients who have been with that condition for more than 25 years. Why? They have been on their medication and some of them have had the valve replacements or valve surgery, so the prognosis I can say is good and sometimes bad for those ones who are not taking their drugs properly.

Interviewer: Okay. And then, tell me about your encounters with RHD patients; do you remember the last time you handled an RHD patient; when was it? When was the last time you saw an RHD patient?

Respondent: huh, every day and even up to date.

Interviewer: Even today you seen one?

Respondent: Yes.

Interviewer: Can you briefly summarize that visit; what was the age, how was the patient, how was the visit?

Respondent: Yeah. Um, they come in normally. The good thing with Uganda Heart Institute, our patients were given that priority of not paying consultation. Why? Not because they are too poor but because it's chronic condition; today they are sick and the following day they might be normal or not normal. So in a week or a month they can come in the hospital twice and you know that consultation fee is too much for them, so they come in at any time. So my patients, the ones I have seen, sometimes they come in when they are really sick.

Interviewer: Like the one you have seen today?

Respondent: The one I have seen today is sick.

Interviewer: He is sick!

Respondent: He needs that surgery.

Interviewer: how old is he?

Respondent: he is 35.

Interviewer: 35! And when you look at his compliance with the treatments, how is it?

Respondent: You know these are the patients who tell you that "I take my medication." but physically when you see the patient, the way he has presented, he is not taking the medication well although he might be deceiving you. So you know that the patient may not be taking that medication well.

Interviewer: what did he present to you?

Respondent: he came with the chest pain, he came in with edema of the lower limb and his dosage of diuretics has been high, but the way he is saying "I have been taking my drug!" is not really convincing me.

Interviewer: Okay. And then, do you think the RHD patients know the association between a sore throat, Acute Rheumatic Fever and RHD? Do you think they see any connection?

Respondent: Yes, these patients who have been with us for some time, we have been telling them that and some of them know, but there are those ones who are new so they might not know. As I told you, the patient comes in and doesn't know anything about that condition but because of that counseling with the patient and the health education, he goes home knowing that "this is a condition and I have to . . ."

Interviewer: Okay. So For the average age of RHD patients, they are mainly females and adults?

Respondent: Yes.

Interviewer: which age did you say?

Respondent: adults, what I can is that from 13 years and above. Children; 3 to 13 years. Can I say that in our Uganda setting; the adult age?

Interviewer: The official one is 18.

Respondent: 18!

Interviewer: so you are talking about 13 years and above and those are the most . . . ?

Respondent: yes.

Interviewer: Okay. When they come to you, what kind of symptoms do they describe?

Respondent: Normally it is the chest pains.

Interviewer: apart from chest pain?

Respondent: It is mostly chest pain and sometimes with cough and that edema of the lower limb.

Interviewer: Okay. And then um, are they good about follow up adherence when you look at them, because you have worked with them for 6 years.

Respondent: some.

Interviewer: which percentages are adhering?

Respondent: But it's only like, very few ones who are not good with our . . . who cannot come to the hospital? One; reason being they would love to come to the hospital but they don't have transport. He/she will tell you "I never came for my review because I didn't have transport" and you are not going to penalize him/her; she comes from far. Our patients really come from far, for example down there in Kisoro.

Interviewer: Eh! They come from Kisoro?

Respondent: Yeah. So you cannot penalize that patient. So what we have to do, we opened up a branch in Mbarara; we tell them “please don't come to heart institute, go to Mbarara” because at least the transport from there to Mbarara might reduce.

Interviewer: part from far those who come from Kisoro which other patients are coming from very far districts?

Respondent: Gulu, Lira, Soroti and all those places.

Interviewer: They come here!

Respondent: Yeah. But those coming from Gulu, the northern part, they can go to Gulu or Lira.

Interviewer: then Soroti?

Respondent: some of them can come here and others go to Lira.

Interviewer: You said you have those branches in Lira, Mbarara, why do you think some keep coming here despite having regional hospitals which can handle it?

Respondent: it's because sometimes they can have that complication which needs our cardiologists here and we emphasize them “if you see that you are really too sick and you need an admission, you'd rather come here” and those doctors who are there know that they refer them here immediately unless if the patient is stable.

Interviewer: so does that mean that the regional hospitals don't usually handle very sick patients?

Respondent: No, unless when the patient has just requested when he has no transport to come here.

Interviewer: Okay. So you said you have those who come and they adhere to the drugs!

Respondent: yes.

Interviewer: what do you think makes them to adhere to the treatment? What motivates them to come?

Respondent: [sighs] what can I say? Maybe because of our service, because we don't give them transport. They know that consultation is free, one, and they get their drugs. Secondly, their injection, the Benzathine injection; here it is less painful here than when they get it from the other side. So they can shoot two birds with one stone; they come for the injection plus their medications. Sometimes we have drugs here than there.

Interviewer: You have brought an interesting thing; “the injections here are not painful”

Respondent: mm-hm.

Interviewer: Tell me more about that. What makes them less painful here and more painful the other side?

Respondent: Yes. As I told you that the other session which we had in the beginning, they told us that we should localize the pain with Lidocaine. So we try to localize that pain with putting the Lidocaine, than those people; they don't know that trick. It's actually these patients who are introducing this trick to them when they go to their health centers. They be like, "Doctor, I have got my Lidocaine; the nurse told me to be mixing it like this and this and then inject" and sometimes they call me and I tell them what to do.

Interviewer: so what do you think should be done for those health workers in the regional hospitals about the way they give the injection?

Respondent: those health workers, what I can say, is the training about RHD. Most of them don't know about RHD although they trained them in school. But you know there are many topics and really you can skip one topic and forget unless when someone has just reminded you. So they should go with that training about the RHD, the cause, signs and symptoms and the treatment.

Interviewer: Okay, thank you very much. And then um, so for the barriers from what you have just said, it looks like transport.

Respondent: mm-hmm

Interviewer: Some people don't have transport to come!

Respondent: Yes.

Interviewer: what else.

Respondent: drugs.

Interviewer: Drugs! What is it about drugs?

Respondent: um, what can I say?

Interviewer: how are drugs a barrier to them coming for treatment?

Respondent: for what?

Interviewer: how are drugs being a barrier to them to come to treatment?

Respondent: no, no

Interviewer: Okay, you talked about, why they would rather come here is because they will get the drugs. Does that mean that um, can I assume that those facilities/regional hospitals where RHD is managed, drugs are lacking?

Respondent: Yes, they are lacking. Why? Sometimes here we might not have one drug for example I can say Spinalactone or Digoxin, so you tell them to buy from outside, and they will tell you, "Nurse, I would rather buy from Kampala than there because in our village there are not there." So they are not there, they would rather come here because they know drugs are available.

Interviewer: and how expensive or cheap are these drugs when they come here?

Respondent: they are really cheaper than they go out.

Interviewer: if an RHD patient came in today, how much can that RHD patient spend on treatment and drugs typically?

Respondent: it depends on the drugs which are not on the government side, because we have got drugs from the government side and those ones from the pay side. So the patient can go without paying for any drug when have got them at the government side. [Receives phone call]

Interviewer: so on your part what barriers do you get when you are providing RHD services? What are the challenges you face?

Respondent: When I am?

Interviewer: When you are providing RHD services: care and management.

Respondent: Actually, the only painful thing on my side is that I am handling very sick patients who are poor. So when you admit this patient, when she is for admission, she will tell you that "doctor, I can't be admitted because I don't have the medical fee." So you try to advise that patient to go there because at least it can waive. Well I am not going to disclose to my patient that we are going to waive for you, but I convince her/him to get admitted here to get the proper medication. At the end of the admission I will try telling him/her, "Please try to raise some money according to the medical bill." Sometimes they raise and sometimes they don't and the hospital can waive for them.

Interviewer: so for those drugs which are not on the hospital, you said you have those for the hospital and those who are not on the hospital!

Respondent: yes.

Interviewer: Like for RHD drugs, how much could a patients pay on average?

Respondent: Actually, my patients, I think, one; sometimes they don't have Warfarin and . . .

Interviewer: It goes for how much per tablet?

Respondent: each tablet is 500shs.

Interviewer: so for 30 days, how much?

Respondent: Now, I can't estimate.

Interviewer: which other drugs is usually needed by RHD patients that has to be bought?

Respondent: Warfarin, Digoxin.

Interviewer: and how much do they spend on that drug?

Respondent: the Digoxin?

Interviewer: yes.

Respondent: Actually I have never taken that urge to know how much.

Interviewer: Okay, so on your side you said that the patients come in when they are very sick and when and they don't have money. What other barrier do you face when you are doing your work?

Respondent: [no response]

Interviewer: None?

Respondent: mm-hmm

Interviewer: Okay. Now let's look at the administration here, how is it, is it favoring you or not. How is it working for you?

Respondent: Here, it's favoring me.

Interviewer: why do you think? Why do you say that?

Respondent: it's okay.

Interviewer: How does it support you in your RHD management?

Respondent: Personally or with my patients?

Interviewer: when you were handling your RHD patients, how has the administration favored you to do your work?

Respondent: it has favored me because they don't have that segregation that these are only RHDs, or no one is going to touch my patient. Every doctor, if I take my patient to him /her, he handles my patient.

Interviewer: he handles them!

Respondent: yes.

Interviewer: Okay. How about the district leadership, does it work for you? When you are handling your RHD patients do you feel they are helping you in one way or the other?

Respondent: What I can is, sometimes yes. Why? We had a challenge with one of our patient and we took that patient of Khartoum, that is Salaam Center for Surgery and unfortunately that patient died. And you know those people, since it is a Moslem country, they had to bury there and then, but we needed our body this way. We had to contact the minister and the body was transported this way.

Interviewer: Okay. So when you look at the funding for health care in general, is it working for you?

Respondent: no.

Interviewer: why?

Respondent: the money is little.

Interviewer: money for what?

Respondent: salary.

Interviewer: Okay. Any other funding issue apart from the salary?

Respondent: Yes, and also what we want is the district or the government to help us with is our INR strips because most of our patients they go on for surgery, they have to be on Warfarin, and on Warfarin, we have to take off blood for INR. You can't take Warfarin without removing off the blood; that blood is the one to give us the dosage, so our patients don't have that 20,000shs per visit. Lucky enough for the past days, we had some funds from out; they used to fund us and our patients used pay only 5,000shs for that blood test and it could work for them properly, but right now the fund, the donor . . .

Interviewer: which donor was that?

Respondent: it was the Case Western

Interviewer: they pulled out?

Respondent: yes, the study stopped and now the patients had to pay for the investigations, I mean that blood test. You know these patients come in and although they are not paying for consultation, but this 20,000shs plus also some drugs . . .

Interviewer: so how are they managing?

Respondent: they are trying, although . . .

Interviewer: do you have some who have gone without the tests?

Respondent: yes.

Interviewer: and what did you do with the doses?

Respondent: Actually, it was nothing. Sometimes, little but not too much, I try to put it on myself and really, they have to be on my bill. At least when I see she has missed like for three times and I can believe that she has not been taking her Warfarin and am scared this patient will get stroke.

Interviewer: Okay. Sometimes you even put in your money!

Respondent: yes.

Interviewer: Okay. Let's look at the numbers of health workers. Are the numbers working for you, the qualifications and training? Let's look at the numbers.

Respondent: the numbers in general?

Interviewer: yes.

Respondent: the numbers in general, we are under-staffed and the work is too much.

Interviewer: what about the qualifications of the health workers here?

Respondent: the qualification of the health workers is improving; it's good because some of them have gone for further studies.

Interviewer: Okay. And then when you look at the waiting time for the patients and the patients you see . . .

Respondent: It's not too much because our doctors are there; they don't wait too much, unless when they are going in for further investigations, that's when they will delay. But if they have come in for out-patients, they don't delay.

Interviewer: for a typical out-patient, when someone is an out-patient, how much time do they spend? An RHD patient.

Respondent: I believe, you know these patients are stubborn, unless if they have come late, it is when they will leave here late. Sometimes they can come at mid-day because they know they will meet Sister so and so who is her friend, and that she will just by-pass and go in.

Interviewer: but typically, how long does a person spend here? If someone came in at 8am, what time will they leave?

Respondent: 10am.

Interviewer: Okay, that's almost two hours. When we look at the medication for RHD, is that working for you? Do you have the drugs? How are the drugs here?

Respondent: Yeah. It's working but the problem is that I wish they can really find the real drugs which can really kill the infection; that's a challenge. You know these are patients who are on Benzathine from the day they have been affected till death. At least let them find, maybe a researcher comes out and they find a curable medicine.

Interviewer: When you look at the heart failure drugs, how are the stocks? Are you comfortable with the stocks?

Respondent: No, I am not comfortable because sometimes we are lacking.

Interviewer: how about the diagnostics, particularly ECHO-CARDIOGRAPHY, are you happy with it?

Respondent: yes.

Interviewer: And how about the BPG and the anti-coagulation drugs? How are they? How are the stocks?

Respondent: BPG is there; it is good

Interviewer: so which drugs are lacking in stock?

Respondent: These anti-coagulants, because sometimes they go on the pay side when it is finished at the government side.

Interviewer: Okay. When you look at the medical records here and the flow of health information here, the health information system here. Here we mean integration of facilities and the in-patient-outpatient registers, so here if you need something about your RHD patient, can you easily get the information or records? How is the flow of information here?

Respondent: Yes, it's so nice and smooth.

Interviewer: why do you say so?

Respondent: Because each patient comes in with his/her card and getting the file is easy and nowadays, we don't use the files; we are using the computer system. So all the information is in the computer.

Interviewer: Okay. Anything lacking in the health information system?

Respondent: no.

Interviewer: Okay. And then in case you wanted to communicate with another health center about your RHD Patient on how to treat him and you have to get the files from there to here, is it easy?

Respondent: from there?

Interviewer: yes, like maybe if it is a referral?

Respondent: For them, when they send, they write down on the referral form what they have done, but mostly they (patients) go there with all our documents. For them they go there with all our documents, for them they treat what the patient has presented that day.

Interviewer: Okay.

Respondent: Yes.

Interviewer: How about the guidelines and protocols, do you have RHD protocols in place; RHD care protocols and care?

Respondent: yes.

Interviewer: have you seen one around

Respondent: yes.

Interviewer: so you have them!

Respondent: yes

Interviewer: so you have the protocols!

Respondent: Yes.

Interviewer: Okay. And then do you have a proper referral pathway that you follow when you are handling RHD patients?

Respondent: yes.

Interviewer: And then um, so you said that what is working for you in the list we have mentioned, you said flow of information is perfect for

Respondent: Yes.

Interviewer: the administration is okay

Respondent: Yes.

Interviewer: So what else has made you work and just continue working with RHD patients?

Respondent: For me, I am not going to say money, no! It is maybe because I just love my job, I can say that. Because if I say money, it's not; me I am a person who can take 2-3 months without getting paid, otherwise I would have even left the place, but it's because I love my patients; I love my job!

Interviewer: So it's the love for the patients!

Respondent: Yes.

Interviewer: And then, um, so generally, do you think the RHD patients get the care they need or not?

Respondent: they do

Interviewer: why do you say that?

Respondent: why do you say that? It is because they meet us on the ground and the doctors on the ground. Even if the patient wants to be admitted, if the patient needs ECHO or ECG, it's done.

Interviewer: What about surgeries?

Respondent: They do. They get the surgery, but not free of charge. Unless when we have get like a couple or donor who comes in and says "I will deal with some patients"

Interviewer: When you look at the patients' safety and quality of care concerns, what are some of the safety concerns you have about your patients here? Do you see any patient safety concerns here or maybe the quality of care concerns?

Respondent. No

Interviewer: Have you had any preventable death occurring? Preventable means surely the person has gone but they wouldn't have gone, but because of the conditions that would have been probably managed but they were not managed.

Respondent: no.

Interviewer: No! There is no single scenario you remember where you felt like no this patient wouldn't have died?

Respondent: maybe when like, I can say, our patient come in late and needs admission and maybe on the time of admission, he kicks off. Maybe if there was a quick means of transport for this patient or maybe if he had an ambulance on the ground, they call us, a standby ambulance runs to that patient . . .

Interviewer: Okay. What are the two most important things Ministry of Health should do to improve the RHD outcomes?

Respondent: Health education; they should come in and support. Why? We need more education on RHD of the health workers because that knowledge we shall deliver it to our patients. And also facilitation, like supporting us on drugs.

Interviewer: Okay. So as we are winding up, what do you think we can do to motivate our patients to adhere to drugs and even come for care?

respondent: What I can say, drugs; if at all they are on grounds, patients will come from wherever they are coming from knowing "I am going to meet my doctors and I will get my drugs" rather than you coming and they tell you, "pay" and yet you don't have that money. Imagine if you are coming from let me say, Mpigi down there or Sembabule, and maybe even the transport you had to first borrow and then when you get here they tell you to pay 40,000shs for the drugs! The patient won't really buy, or she will buy for like a week . . .

Interviewer: besides drugs, what else?

Respondent: Even the space; we have got limited space. We send our patients to the referral hospital and they can say they may not get good care. Sometimes they can tell you "doctor, we are going" but what I have experienced is that they don't reach there because they know that they are not going to get the service there. She will end up dying from home, and when you end up calling to inquire, the family members will be like, "doctor we never took our patient there; she died from home."

Interviewer: they don't want the referrals because they know they won't get the care they need?

Respondent: yes.

Interviewer: anything else before we wind up?

Respondent: no.

Interviewer: thank you so much nurse for your contribution to this study. Just to remind you, we are going to keep your information confidential and it's going to help us to come up with better programs for RHD management. Thank you very much.

Participant ID	HW 002 -Wakiso
Date	20 /Mar/2019

DOCTOR

DATE: 20/03/2019

VENUE: UHI TEA ROOM

Interviewer: So this is the date of 20th March, 2019 and we are seated here in the tea room of UHI talking to one health worker. You are welcome.

Respondent: Yes. Thank you. The tea room of UHI in the outpatient department.

Interviewer: Thank you so much. So basically we are going to have a conversation about what we have discussed and I request you to be frank with your answers as you share your opinions and there is no right or wrong answer; whatever you say is what we want to hear. And then your identity is going to be kept anonymous. Tell me a little bit about yourself; how old are you?

Respondent: I am [REDACTED] years old.

Interviewer: What are your qualifications?

Respondent: I graduated with [REDACTED]

Interviewer: Those are [REDACTED] years?

Respondent: Yes. I have been working in Uganda heart institute since [REDACTED]

Interviewer: Those are [REDACTED] or more years.

Respondent: Yes, [REDACTED].

Interviewer: okay. Actually you have answered my second question. It was how long ago were you qualified? So you have been here for [REDACTED]. So when you look at the patients you are dealing with here or you dealt with in your practice, what are the common illnesses you see here?

Respondent: Hope it's not a bit of bias because since I qualified I have been working in Heart Institute; I don't do private practice so most of the patients we see here are patients with heart problems.

Interviewer: Like which ones?

Respondent: The commonest in adults is hypertension which usually comes in with co-morbidities like diabetes, then we see rheumatic heart disease, pulmonary embolism, we see patients with myocardial infarction, and commonly patients come here when they are in heart failure and there are various causes of heart failure, a few of which I have mentioned.

Interviewer: So when you look at the demographics, are they the old, young? Are they male or female?

Respondent: Okay the demographics; the ages is that we see all ages here. But maybe what I can say concerning diseases like hypertension is that most of the patients are quite aged about 50 years. And maybe the ones of Rheumatic Heart Disease all the age brackets are there but commonly maybe between 15-50 years, although there are those who are above 50 years but still come with Rheumatic heart disease.

Interviewer: Good. And then, let's look at your training in RHD; have you received any specific training during school?

Respondent: like specifically a training on RHD?

Interviewer: Yes

Respondent: No.

Interviewer: How about in school, did they talk about RHD?

Respondent: Of course in school there are tutorials, there are lectures, you have combined group discussions about the various topics and of which, one is RHD.

Interviewer: And then after graduation, have you had any specific training in RHD management and care?

Respondent: No.

Interviewer: Do you think you need one?

Respondent: It would be very important you have one maybe in form of frequent CMEs and going to people to train you. It could be very helpful because many patients have the disease.

Interviewer: So which specific areas would you want to be trained in?

Respondent: I think it would be important to do the preventive bit.

Interviewer: Preventive bits.

Respondent: Yeah. Or catch it early, manage whatever they have to avoid the complications.

Interviewer: So umm, in a day, typically how many patients do you have?

Respondent: That depends because there is the outpatient department and the inpatient department. So if you are in outpatient, maybe an average you can see 13-15 but there are days when they are as few as 10 and some days when they are as many as 25.

Interviewer: in a?

Respondent: In a day, in out-patients! Then on the ward (in-patients), maybe in a week they could be 3, 4 or 7. I have not really taken kin interest in the inpatient units to know how many could be there.

Interviewer: So you have more out-patients than in-patients?

Respondent: Yes.

Interviewer: So what is your understanding on the causes of RHD? What were you taught about it?

Respondent: RHD is Rheumatic Heart Disease and this occurs as a complication of Acute Rheumatic Fever, and Acute Rheumatic Fever usually follows someone who has had a sore throat or pharyngitis which is commonly caused by a bacterial infection, and the type which causes that is a Group A streptococci.

Interviewer: Are you aware of the link between a sore throat and RHD?

Respondent: Yes, of course most of these patients may not recall because the RHD comes in years later, but there is a link; you have a sore throat then followed by rheumatic fever and then the rheumatic heart disease.

Interviewer: What were you taught can be done to prevent RHD?

Respondent: I think importantly is that once someone has a sore throat, treat it adequately with the right drugs and complete the treatment, and it would be good to follow up to see that they are getting better.

Interviewer: What were taught about the treatment of RHD?

Respondent: The treatment of RHD.

Interviewer: Yes, the treatment.

Respondent: In RHD you have permanent damage to the valves, though some people can get recurrent infections and they get like a Carditis where all the hearts layers, the muscles, are affected. So it depends, but usually patients are given drugs to help with the functioning of the heart and there are very many groups of drugs that can be given. Maybe I could say that the anti-failure drugs, then there are those who have, as a result of damage to the heart, some of them

can form clots so you can give anticoagulation or if they have arrhythmia issues which can predispose them to form clots, you give them anticoagulation.

Interviewer: Okay.

Respondent: and maybe importantly to note is that if these patients are on drugs and they are taking their drugs as prescribed they would be stable but it's also good to look out for other factors which can keep precipitating them into getting heart failures.

Interviewer: Okay, so what is your understanding about the long term prognosis of RHD?

Respondent: long term prognosis?

Interviewer: Yes.

Respondent: I think this depends on how these patients are managed; if given the right treatment, the right doses and they are keeping the follow ups I think they can be . . . and depending on how severe the valves are damaged, they can last for some time. I will not put a year to it or months or anything, but I think with appropriate treatment they can survive for some time. The point is that if they have severe disease and they are having frequent admissions for heart failure and also if they qualify to be operated. If they are operated, many patients here have been operated and they are stable; they are living normal lives.

Interviewer: So tell me about your encounters with RHD patients; do you recall the last patient you saw with RHD?

Respondent: [laughs] Of course, I have just seen one.

Interviewer: Can you summarize how s/he was?

Respondent: The last one was stable; her disease isn't major. She has had surgery, she has been coming for follow ups, she is taking her drugs to the dot and she is stable. The only thing that she does is to keep checking in the INR to see that, you know one of the drugs we give is the Warfarin's, so we have to check to see that it is within the required therapeutic range.

Interviewer: Did she have any complaints today?

Respondent: she told me that she has just come in for review because they told her she had to come back for a follow up.

Interviewer: Wow! Okay, and then um, when you look at the average age of RHD patients, who are they?

Respondent: Average age!

Interviewer: Yes.

Respondent: Maybe I would say 25 years, but there are those extreme ages that I have seen here.

Interviewer: But most of them are how old?

Respondent: 25 to 30 years; many are there.

Interviewer: So are they working or not?

Respondent: Some are working, some are . . . I don't know, but maybe they feel sorry for themselves and they don't work because some of them you see that they are stable, and can do something but they tell you "I am not working." However, majority are working and some are at school.

Interviewer: Do you think that they know the link between sore throat, ARF and RHD? Do they know that those three are . . . ?

Respondent: I have not taken that kin interest to find out from them, but I would think that those who have got some bit of education, on the initial encounters they had, they must have been informed about it but I don't know if they can recall.

Interviewer: So the initial visits, do they come with that prior knowledge that probably this . . . ?

Respondent: No, we just give them the information.

Interviewer: okay. What sort of symptoms do they usually describe when they come especially for those first visits?

Respondent: For the first visits, some of them may complain of a sore throat, some of them may complain of joint pain or chest pain, and some of them come in with heart failure symptoms and they are diagnosed when they are in heart failure. Like that's their first encounter, they are very sick, they do the tests and they find out that they have RHD.

Interviewer: Okay. When you look at their follow up and adherence, what do you have to say about it?

Respondent: Here where I work, follow up and adherence is very good.

Interviewer: It's good?

Respondent: Yes, it is very good. Of course I wouldn't say its 100% because there are always those few whom you would explain to "take this and this, like this" and then they come back and tell you something totally different, but at least on average it's good.

Interviewer: What makes it good?

Respondent: I think what makes them adhere to treatment is, I think it comes from the health workers; if you talk to someone and they understand their disease and the importance of the drugs, and also possible side effects which could come in. Because, they might stop because of the side effects which you could have not told them at the beginning, so if they know about the disease and you tell them why you are giving them the drugs, adherence would be good.

Interviewer: Do you have some who are just not adherent?

Respondent: Those who do not adhere, um, those who don't adhere, usually those incidences come in some of course in in-patients and some in-outpatients but it occurs like if you have given them 4 drugs and like the 2 of them are off. So they tell you that "drugs went off, I couldn't come back, or transport issues and you gave me drugs when there were a few days left to come back for review and I couldn't buy drugs." So basically like that.

Interviewer: So its transport . . .

Respondent: Yes, transport, and some of them say that where they live, the drugs given here are not there.

Interviewer: okay. And then um, have you had an experience where by you prescribed and the patient didn't get the drugs and they have to go away without RHD drugs?

Respondent: That maybe be hard to say because in the consultation rooms usually when you prescribe, you direct them to the pharmacy and tell them "there is this pharmacy and there are drugs for free and there is this pharmacy for buying." So when they get out, you may not be able to follow up. But most of them come back and they tell you "I have been taking my drugs" so most probably they got their drugs but not sure if they got their drugs from here or outside.

Interviewer: Okay. What sort of barriers do they commonly state to getting their care; you have talked about the transport . . .

Respondent: Yeah, there is transport, social support, um . . .

Interviewer: Okay. What else?

Respondent: those are the common things.

Interviewer: those are the common things because you have talked about drugs not being where they stay and then transport.

Respondent: Yes, finances are basically the common thing.

Interviewer: okay, and how about your care providers; what sort of barriers do you face?

Respondent: [laughs] Barriers in care!

Interviewer: Yes. You know you want to treat your patients but you are limited.

Respondent: [laughs] let me just think through and see . . . [thinking]. Would having more time with the patient be a barrier? I think it would be nice to have more time with the patients. You can explain to them and talk to them but sometimes if the patients are many and you have to see everyone, though they are not usually many but there are those particular days when they are.

Interviewer: You don't get enough time to really talk to all of them?

Respondent: Not on a daily basis but there are those few days.

Interviewer: Any other barrier?

Respondent: Personally, maybe that.

Interviewer: How about the time when you are giving treatment, are you limited by anything?

Respondent: Not really except for those few incidences where patients are allergic to the injection and then bad news happens, but not really. Because when you're giving these drugs, you inform them the side effects and the interactions possible in the easiest language they can understand, though some things can't be translated in the language they understand. So when you tell them that "when you see this, come back immediately" although some of them might end up stopping the drugs and when they come back for review, they have not been on that particular drug which they think is causing them trouble.

Interviewer: um, so there are some explanations you give but you don't have the right simpler words to use when you are attending to them?

Respondent: Yeah that too.

Interviewer: Okay. And then let's look at the local health system barriers, we want to see which pieces are not working for you and why you think so?

Respondent: Sorry which what?

Interviewer: The local health system barriers, in this we have the administration, the... let's go one by one and you tell which one is not working for you and why? Let's look at the administration here and at the district level; is it working for you in any way?

Respondent: I think they are.

Interviewer: Why do you think?

Respondent: although I might not talk much about the district level; it might be hard.

Interviewer: Okay.

Respondent: At least seeing these patients, there are particular people who see them and those people are present every day; patients get to be seen, prescribed drugs, they get their drugs and in case they have any questions, they get to ask.

Interviewer: So you are comfortable with the administration here?

Respondent: Yes I am but maybe the only thing I see is that sometimes the patients wait for too long especially those who have to do blood tests like INR and those who have to do follow-up Echo's, sometimes they wait for long.

Interviewer: Like how many hours do they wait?

Respondent: Maybe 3 to 4 hours.

Interviewer: So how can we improve that?

Respondent: um, maybe they could put, anyway it might be challenging, but maybe they could put particular days for particular conditions and maybe these patients get to be reviewed the following day so that they don't spend much time here. But that would come with the financial implications on their pockets to come two days (twice).

Interviewer: So that's administration. How about funding for health care in general; how is it, is it working for you?

Respondent: Particularly for this?

Interviewer: Let's begin with general funding for health care.

Respondent: General funding for health care! Of course I would talk about the things I would want to use as I work on a patient. You would find that some, okay I have worked in a different setting; a government setting outside there, but sometimes you want to really attend to a patient but you can't attend to them unless you have things like gloves. You want to do a blood test and you don't have strips, like availability of, are they equipment or resources? Those things you must have to work on a patient; sometimes they are so limited.

Interviewer: How about here? How are the stocks?

Respondent: Here?

Interviewer: Yes.

Respondent: [sighs] the stock here are fairly Okay, but there are those days when you don't have like RBS strips those tinny things which would make work easier.

Interviewer: How about when it comes to RHD management, how do you look at the funding? How is the funding?

Respondent: Here in Heart Institute the funding is good and I would like to take the opportunity to thank whoever is out there funding these people, because many of these people are quite or really needy and they would not afford to even buy the drugs. We appreciate the support.

Interviewer: okay. How about elsewhere, how do you see the referral hospitals which are handling them?

Respondent: Referral hospitals, it's troublesome! Because the patients referred here sometimes you find they have prescribed drugs but they are not on drugs because they are not there and they can't buy them. Once they reach here, you tell them that they will be registered under RHD, be seen for free, the drugs will be there . . . So maybe it would be good if they have RHD centers.

Interviewer: Okay. Let's look at the health workers' numbers and qualifications; are they working for you?

Respondent: Yes they are working for me here.

Interviewer: why do you say so?

Respondent: At least every day there is a doctor to look at these patients and after that the pharmacist is there to give them the drugs, and after that there is a RHD nurse who writes down drugs to them and then they come back.

Interviewer: How about the numbers?

Respondent: The numbers of the health workers?

Interviewer: No, that one, you said that they are enough, but how about the number of patients that you as health workers see in a day. How are they?

Respondent: The numbers keep on fluctuating but on average, I think it is okay.

Interviewer: How about the medication! Let's look at BPG, the anticoagulation drugs and heart failure drugs; how are the stocks?

Respondent: Here in general or?

Interviewer: Here

Respondent: The stock here is good.

Interviewer: okay. Any gaps?

Respondent: No.

Interviewer: No! How about the diagnostics especially the Echoes?

Respondent: They are Available.

Interviewer: Any gaps?

Respondent: What I would say would be the waiting time; other things on average are okay.

Interviewer: The waiting time! And then the way you keep your records; how does the health information flow? Is it working for you between the out-patients and the in-patients and the registries? What do you have to say about this?

Respondent: The RHD registry is working well; you are able to retrieve patients' documents, you are also able to retrieve drugs, you are able to retrieve anything you want about the patients; there are contacts. Basically, it would be hard to look for someone with RHD and they are in the registry and anytime you want them you don't get them.

Interviewer: So it is working well.

Respondent: Yes.

Interviewer: okay. How about the ARF registries, are they also inclusive?

Respondent: That one I am not so sure.

Interviewer: Okay, and then the guidelines and protocols; do you have the guidelines? What do you have to say about the RHD care guidelines and protocols? Do you have them in place? Are there guidelines and protocols in RHD here?

Respondent: Yeah, but it would be nice, of course you have the information and the exposure but maybe it would be nice for those rooms to have brief chats on it for people who don't know about it, even the patient's themselves can read about it and see that those are notes.

Interviewer: Do you have CME sessions here about RHD?

Respondent: The sessions are there but not often.

Interviewer: Not what?

Respondent: Often, because here they conduct themes every Friday, but they are not specific to RHD. So if the case of interest is RHD, then they can talk about RHD.

Interviewer: And are people given opportunity to go and attend?

Respondent: Everyone is welcome to attend.

Interviewer: Do they attend?

Respondent: The turn up is not usually good, [laughs] but everyone is allowed to attend.

Interviewer: What makes it a little bit low? What do you think?

Respondent: It's usually Friday some people might be off, hmm! Then there are those people who just come late, but they announce; people get to know because they put a notice on the notice board. It is not that people just don't know.

Interviewer: People just choose not to come?

Respondent: Yeah for some reason's.

Interviewer: So from what we have mentioned; administration, funding, health care, medication, you said most of the pieces are working for you apart from funding . . .

Respondent: . . . waiting time.

Interviewer: And the waiting time. The numbers of health workers are working for you, at least there is a doctor!

Respondent: Yes.

Interviewer: You found the administration okay.

Respondent: Yes.

Interviewer: And the medication, right?

Respondent: Yes, but the emphasis would maybe be to have working units in regional referrals and other lower places. It would be good people would not have to travel that far to come here.

Interviewer: so apart from the local system, what else has motivated you to keep seeing these Patients?

Respondent: It's good if you see someone that you are managing and they are improving. You feel rewarded, you feel better when the patient is feeling better.

Interviewer: okay. So generally, do you think these RHD patients get the care they need? When you think back, do they get the care they need?

Respondent: Medically they do, but via those who need surgery or those who have surgical disease, I think many are delayed. Still it goes back to finances for those who have to pay for the

surgery because it's costly, and then there is that other project in Salaam Center; I think they offered to operate on some people with RHD but they come and assess and I think people are put on the waiting list depending on how severe the condition they are in.

Interviewer: So tell me about the patient's safety and the quality of care concerns you have around here. Is it put into consideration? The quality of care the patients get, are there any concerns you have as a person working here?

Respondent: [sighs] the quality of care the patients get, I would say it is standard treatment that they get. Concerning the safety bit, I don't know; what exactly should I talk about safety? Is it record keeping, drug effects?

Interviewer: Safety can mean a lot, but first and foremost there are some deaths which occur because the patient was not well managed. Have you had such?

Respondent: Yes, in my short practice [chuckles], yeah, we get one or two.

Interviewer: Can you tell us what happened?

Respondent: I think this patient was on anticoagulation and then she got a subdural hematoma if I remember well, and there was a time lag between getting the Neurosurgeon, coming to work then the follow up and we ended up losing the patient. Though they had worked on the patient, there was a bit of time lag.

Interviewer: Any other you can remember?

Respondent: Any other? No.

Interviewer: okay. So if someone asked you "how is the quality of care of patients here? What would you say?

Respondent: On average, good.

Interviewer: On average good! Why not 100%? What is lacking?

Respondent: [laughs] it can't be 100%.

Interviewer: You think it can't be?

Respondent: At the moment that is what I think.

Interviewer: So what do you think can be done in the future to shoot it to 100%?

Respondent: I think if you get people to specifically attend to these patients, um, given priorities when they are doing these investigations. Of course here Echo is done for free and consultation is free, but there are those other blood tests that they have to go for. If there is more funding for that, it would be good to go.

Interviewer: So this is the last one. Do you think patients are dying in communities without presenting to the hospital for proper treatment?

Respondent: There could be some. An example is of some boy who is on ward right now; he is 15 years old but he came in when he was all swollen, hardly breathing, coughing, very weak, and he had been in the village without coming to the hospital. The moment he came here, he was diagnosed with RHD; he started on treatment and he has bad disease. All his disease is severe and he would benefit from the surgery. But giving that example, I think there are some patients out there who may need help.

Interviewer: After talking to that patient, what could have led to the delay to come here?

Respondent: The mother is always saying "I don't have money. I don't have money for even feeding, so where will I get money for treatment?" Yeah.

Interviewer: So what are the two most important things that the MOH can do to improve the outcomes? What are those things?

Respondent: I think first of all they should, like the way they sensitize for these other disease conditions, there should be people out there talking about how RHD comes in, the initial stages, people should seek health care and even people at the lowest health facilities should have an idea of how to diagnose and treat it appropriately in the government setting. In the government setting which is purely government, they should endeavor to have drugs, supplies and the tests should be done in those settings not necessarily in specific places or private settings.

Interviewer: Anything else as we finish?

Respondent: Just to appreciate the funders.

Interviewer: Okay, thank you very much for giving us your time and your opinions. These will help us to come up with programs to improve RHD arrangements. Thank you very much.

Participant ID	HW 003 -Wakiso
Date	Mar/2019

CLINICAL OFFICER

DATE:

INTERVIEWER:

Interviewer: so tell me about your age; how old are you?

Respondent: I am [REDACTED] years old.

Interviewer: Tell me about your qualifications and where you trained from.

Respondent: I am a [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Interviewer: So how long? You said you have been qualified since [REDACTED].

Respondent: Yes, since [REDACTED].

Interviewer: So how many years are those?

Respondent: That's about [REDACTED] years.

Interviewer: How long have you been working here?

Respondent: Here at Kajjansi?

Interviewer: Yes.

Respondent: This is my [REDACTED] year.

Interviewer: [REDACTED] years!

Respondent: It's in [REDACTED].

Interviewer: So you have been working here for the past [REDACTED] years!

Respondent: Yes.

Interviewer: Okay. So this is the clinician's room?

Respondent: Yes, this is the clinician's room.

Interviewer: It's where you see patients from!

Respondent: Yes, it's where I see the patients from.

Interviewer: So tell me about the demographics of the patients you see here; what kind of patients do you see and what kind of diseases do they present with?

Respondent: Okay. It depends on the season; during this dry season people mostly come with cough, flu, fever, sore throat and skin infections, but when it's the rainy season that's when you will find that they come mostly with fevers and diarrheal diseases. We have a slum here called . . . the hygienic condition of that place is not good that in during the rainy season we get the most diarrheal cases.

Interviewer: what kind of age groups do you usually have of the patients that come here?

Respondent: We have young children from let me say, 2 months up to 90 years, because we have a diabetic clinic on Thursday and Friday and also an eye clinic on Thursdays. So mostly on Thursdays the elderly come mainly because they know that there is a diabetic clinic where we test them; for the eyes, we do eye screening on that day. So on Thursdays, the elderly are many but on the other days you would find the children and middle aged.

Interviewer: Tell me about your training in RHD; do you have any training on Rheumatic Heart Disease?

Respondent: Just as a special training?

Interviewer: Well any training, whether in school or . . .

Respondent: In school, we were trained; when we were in medical school we were trained about RHD but after qualification, I have not had any special training for Rheumatic Heart Disease.

Interviewer: So you have not had specific training!

Respondent: No.

Interviewer: But you had some training during school!

Respondent: During school, yes.

Interviewer: But after that you haven't!

Respondent: Yes.

Interviewer: Okay. So have you received any training since graduation? I mean since graduation when you became a medical officer?

Respondent: On what?

Interviewer: On Rheumatic Heart Disease.

Respondent: No, I have not.

Interviewer: You haven't! So how many patients of Rheumatic Heart Disease do you often see in a day, week or month?

Respondent: huh, it's very rare. Here! It is very rare, or maybe sometimes, let me say in a year I can see maybe two.

Interviewer: In year?

Respondent: Yes.

Interviewer: What about patients who come with Acute Rheumatic Fever?

Respondent: Acute? The problem with that is that sometimes we miss them because people come with fever, they come with a sore throat, and they come with maybe general body weakness . . . Because when I auscultated the heart sound, I was hearing some murmurs. So what I did, I referred that patient Uganda Heart institute. I think that was last year.

Interviewer: That was last year!

Respondent: Yes

Interviewer: So what is the average age of patients you usually see with Rheumatic Heart Disease? Although you see them rarely, what is the average age of patients you usually see?

Respondent: They are just young people, like in 20s. Most of them are in 20s.

Interviewer: So most of them are in twenties! Are they working or not? Are they in school or?

Respondent: They are working and also some are students. Most of those we have seen are students.

Interviewer: What kind of symptoms do they usually describe?

Respondent: Some of them come with fevers, headaches, sore throat and then the general body weakness, and because of the sore throat that's why they have painful swallowing and so on.

Interviewer: Okay. So generally, what about follow up and adherence; for those you have seen although they are few, do they usually adhere to treatment?

Respondent: yeah, they adhere to treatment because what I usually do is that when I maybe give them amoxicillin and so on, because I may sometimes give them PFStat for maybe five days, when they have completed treatment I usually tell them to come back and then I review again. When I see that there is improvement, I tell them to ensure that if there's more or the symptoms persist or if they get that same sore throat within 1 or 2 months, so when they come back again, what I do is to just give them Benzathine.

Interviewer: So what sort of barriers do they usually or commonly state to taking the care they need?

Respondent: Here the barrier, in most cases is that sometimes they are mismanaged. Because, somebody can come here with maybe a sore throat but you give an antibiotic with no Penicillin in it! But we also attribute that to maybe lack of enough knowledge for some of the staff. Then the other barrier is that they sometimes come when we don't have any antibiotic in the facility. If you had come here last week, because we got our supplies on Friday, but if you had come here on Wednesdays, we didn't have Benzathine, Amoxillin and even Septrine was not there. I think we had only remained with a few stocks of ampicillin injections. That also brings about the issue of mainly the supplies.

Interviewer: So the main issue you have is mainly the supplies!

Respondent: Yes.

Interviewer: Because my next question was like; what kind of barriers do you perceive they face in getting the care they need? And like you said earlier that the main issue they face is when they come here, sometimes the drugs are not there.

Respondent: Yes

Interviewer: So besides that, do they find the health workers there all that kind of stuff?

Respondent: In most times we are there, because we ensure that there is staff at the facility 24/7.

Interviewer: Mm?

Respondent: Yes

Interviewer: Okay. Now I am going to ask you about the local system barriers; which of these pieces is not working from you and why? I am asking about administration and leadership at the district in regards to RHD.

Respondent: Okay, the district . . . because I am sure what they would have done maybe, because you are telling us that at the Uganda Heart Institute there are many cases from Wakiso, and I am sure that when they go for these National Health Assemblies, some of these findings are shared and the DHO attends. So I think from attending those health assemblies and they find out that we have many cases at the Uganda Heart Institute, I think they would have come and informed us about it, but they have been informing us about immunization and so on. However, with the heart, if they had informed us about it, I think we would be vigilant and if you see any patients with sore throat to make sure that they get the right treatment, or that instead of giving them other antibiotics without Penicillin, we make sure that everyone . . . because sometimes you may find that maybe it is the nurse who is seeing the patient, we ensure that we empower them also. So the district had that weakness but good enough you came on board and educated them and they called us also. So I am sure that we are also on board now.

Interviewer: So funding for health care in general, how do you see funding? How do you see funding of this health Centre in general and in regards to RHD?

Respondent: The funding, like government for example, for us with supplies and so on, the government puts money in National Medical Stores and the funding was not good because for this financial year, they have put there 22million for the whole financial year!

Interviewer: For this facility?

Respondent: Yes, just for this facility.

Interviewer: For these number of patients!

Respondent: Yes, 22 million, but they have promised us that in the next financial year, we shall get the health Centre IV kit and they would have increased our funding from 22 to 150 million. So I'm sure that come this July this year, I think the funding would have improved.

Interviewer: But that's in general.

Respondent: Yes.

Interviewer: But in budget is there funding for Rheumatic Heart Disease?

Respondent: Yeah, because now when they went for the procurement plan, what they were emphasizing is that they looked at non-communicable diseases. They told us we have to ensure that we plan for those diseases like hypertension, diabetes, and screening for cancers and so on, and also Rheumatic . . . I am sure Rheumatic Heart Disease will be taken in that same category.

Interviewer: So health workers; how many health workers do you have here? What are their numbers, qualifications and how long do the patients take to wait?

Respondent: Okay, now in this facility we have 32 health workers. Okay, 30 because 2 are cleaners. So its 30 health workers and 3 of them are on study leave. So we have got 2 senior clinical officers; we are two, and then we have a Senior Nursing Officer. With the nurses, we have 2 Nursing officers; one is nursing and one is a counselor. We had a midwifery nursing officer but she left; she went to nursing school and is now a tutor. Then we have like 5 enrolled nurses including those with enrolled psychiatry. Then we have like 4 Enrolled Midwives because of the heaviness of this facility. Then we have got a Dental officer, etymology officer, we have a Health Educator. Good enough our health educator is also a clinical officer by training, so she also helps us when we are clerking patients. Then we only have 3 Nursing Assistants but we make sure that we don't allow a Nursing Assistant to see a patient; we make sure that we have a nurse or a clinical officer around all the time. Nursing Assistants are usually at the dispensing side, immunization and so on.

Interviewer: So which means that according to the numbers of health workers you have, you are not badly off!

Respondent: We are not badly off.

Interviewer: So the medications like Benzathine penicillin, anti-coagulation and heart failure drugs, do have those?

Respondent: We don't have. We Benzathine but we don't have these anti-coagulation drugs because, even Aspirin is one of them but we don't even get Aspirin.

Interviewer: You don't get Aspirin from NMS?

Respondent: We don't; this facility doesn't get Aspirins.

Interviewer: What about the Warfarin?

Respondent: Warfarin, we don't.

Interviewer: Is it because it's a Health Centre IV or?

Respondent: It's a Health Centre IV but getting the supplies of a Health Center III.

Interviewer: Wow!

Respondent: Now even in our hypertensive clinic they (patients) just buy Cardiac Aspirin. Because if it was there we could have been packing for them, but the rest like Nifedipine and so on, we give them.

Interviewer: So one of the main issues you have is supplies!

Respondent: Yes.

Interviewer: And they give you Benzathine but in limited amount!

Respondent: Yes, they give us in limited amounts.

Interviewer: Because you are at a different level but getting drugs of a different level!

Respondent: Yes.

Interviewer: Okay. So Health Information and medical records; how is your medical records system, integration within the facility for in and out patients? Do you have registers?

Respondent: We have registers.

Interviewer: Medical registers?

Respondent: Yes, medical registers in all the departments.

Interviewer: And how do you save your information or data?

Respondent: Which one? The monthly or?

Interviewer: For example, now you are seeing patients, where do you keep your data?

Respondent: Now this information is put in a register and after the register is full, we have a place where we keep all the registers. The Health Information Assistants keeps them.

Interviewer: Okay. Do you have an electronic system where you keep all data or you only use the books?

Respondent: The electronic is done for the reports; after extracting the reports, we put it in the system. Then the electronic for patients is only done at the HIV clinic; from there we have a computer where we enter all the details.

Interviewer: Only at the HIV clinic?

Respondent: Yes. That one we use it.

Interviewer: Do you have any registers for Acute Rheumatic Fever?

Respondent: We don't have a special register

Interviewer: You don't have specific registers for specific patients?

Respondent: No, we don't have; it's a general register.

Interviewer: Okay. Has the health ministry provided any guidelines or protocols for Rheumatic Heart Disease and care?

Respondent: No, not yet.

Interviewer: Okay. What are the local health system enablers? Which of these pieces is working for you; Perception of patient outcomes? Generally, do you think the patients are getting the care they need or not?

Respondent: They do. Now when a patient comes, I can see that patient very well, I even health-educate the patient very well and tell him/her what they are suffering from, give a prescription and also health-educate. For example, for sore throat I can say, "I am going to give you these antibiotics but there are other things you can do like using salty water which can work." Then I take them to get the injection, pain killers and so on. But sometimes when the supplies are not there, I can do all this, but at the other side where they are supposed to get the medicine, that's where the charges comes in.

Interviewer: So that's when they have to buy the medicine?

Respondent: Yes.

Interviewer: So this means that the patient would have got the care but would not have got the medication!

Respondent: Yes, but sometimes maybe when I write Benzathine, sometimes when they buy it, they bring and we inject them.

Interviewer: Tell me patient safety and the quality of care concerns; do the patients feel safe? How is their quality of care? Have you had any incidents where . . .?

Respondent: It used to be there in HIV (clinic) but we have now minimized it. Because, for instance in the case of HIV, the results had some issues but now days after counselling the patient, because those days when I had just come here, whenever a patient was tested HIV positive, anyone could know. But nowadays we have minimized that; we have counselors so we refer those patients there and they do everything there; you cannot know who is positive or negative. And even here for the other cases, we ensure that there is privacy; we sit with them here and do everything here, but for children, sometimes when they are many, sometimes the ward clinician sits the other side and the children sometimes are seen from outside there

Interviewer: Outside like in the corridor?

Respondent: No, not outside; I mean out there where we were seated. When we are two, one sits the other side and make sure that the adults are seated inside here while those with children, we see them from the other side.

Interviewer: Which means that your patients are safe their confidentiality is ensured!

Respondent: Yes, they are safe and their confidentiality is assured.

Interviewer: Okay. Do you think patients are dying in the community without presenting to the hospital for care?

Respondent: Yeah, I think some of them die but we have got a VHT system and each VHT (personnel) is assigned a household. They ensure that they go to those households with patients and they are sent to facilities. Sometimes we have been, like now for TB, we oriented them one time and told them "whoever is coughing, make sure that they come." Some of them (community members) were refusing but we involved the LC (Local Council). On time we had a multi-drug resistant TB patient, we referred the patient to Mulago but the patient took off and came back to the village. People from Mulago Hospital came here and they were looking for that patient, until the community sat and the Chairman told him "we are going to chase you away from the village!" So the patient had to agree and went back to Mulago. So our VHTs

have helped us in ensuring that those people who are in the villages are sent here. They die but nowadays, with the improved VHT system, it is minimal.

Interviewer: So according to you, in your opinion, what would be the most important things Ministry of Health would do to improve the outcomes of patient care generally and Rheumatic Heart Disease?

Respondent: What Ministry Of Health can do?

Interviewer: What in your opinion are the one or two most important things Ministry Of Health can do to help improve?

Respondent: One, they should increase funding in the facility and with funding, so that we can also . . . we have health inspectors and health assistants and they are people who do home visits and so on. So maybe if they increase funding, we can know that if we are having a patient A, B, C who is suffering from Rheumatic Heart Disease, so when we are going for those outreaches, we can know that in Location A if you have gone for maybe immunization, HCT and so on but there is a rheumatic heart patient around, after doing that activity, you can do a health visit; you can go to that home and see. Then it also helps the health educator when there is enough funding. Those days we had some funding and the health educator could go to the villages and do health education, and if the funding is enough, we can engage the health educator to move maybe to the sub counties, maybe when there is a council meeting; he goes and orients them. You know those people also have where they come from; so if you tell them, "If you have a sore throat please you go to the facility." Some of them will go and be diagnosed early and maybe treat the sore throat which, because of the complications or side effects of the sore throat, will prevent you from getting them. So if we orient those councilors and so on, I think it will ensure that Rheumatic Heart Disease cases goes down. So, it is the funding.

Interviewer: What about training?

Respondent: I have told you about it already; we need funding and training.

Interviewer: And also dissemination of that information to the lower facilities.

Respondent: Yes, to the lower facilities. Good enough, you came late but there is a new policy which is coming called Result-Based Financing.

Interviewer: Yes?

Respondent: Through the Ministry Of Finance, Ministry Of Health and World Bank, our facility was assessed and we are through. So we have started the planning system for the next financial year and these are some of the things we are going to put in our work plan so that the health educator, in all his/her activities, we have to include Rheumatic Heart Disease. Because, with hypertension and diabetes, that one we did it and now we have like 500 clients in our clinic. So I think that if we get the funds, we are going to include Rheumatic Heart Disease such that when the Health educator goes out, he can educate the people so that they come early to the facilities and those who have the symptoms, they can come and we assess them and we see whether we retain them here or refer them to Mulago.

Interviewer: Thank you so much.

Respondent: You're welcome.

Interviewer: Basically that was my last question.

Respondent: Wow, wow, wow

Interviewer: Thank you so much for your time.

Respondent: Thank you too.

Participant ID	HW 004 -Wakiso
Date	Mar/2019

Interviewer: So we are at Kajjansi Health Centre IV and we are in the clinician's room, and um, we are having a discussion about rheumatic heart disease; building a case to rheumatic heart disease and control in a resource limited setting. So tell me about your age; how old are you?

Respondent: I am [REDACTED] of age.

Interviewer: [REDACTED] years of age. Tell me about your qualifications and training, whether you did nursing or medical school.

Respondent: I hold [REDACTED]
[REDACTED]

Interviewer: Where did you finish [REDACTED]?

Respondent: I got the [REDACTED] that's what I remember.

Interviewer: Okay. How long have you been qualified?

Respondent: it's nearly [REDACTED] years now in practice.

Interviewer: [REDACTED] years!

Respondent: yes, in practice.

Interviewer: Okay. How long have you been working here at Kajjansi health center IV?

Respondent: it's been [REDACTED].

Interviewer: Where were you working previously?

Respondent: Basically, I was [REDACTED]
[REDACTED]

Interviewer: So you have been working here for [REDACTED]!

Respondent: yes

Interviewer: So tell me about the demographics of your patients; the patients you see here.

Respondent: In children, of course we have They are children with diarrheal diseases, pneumonia, malaria, worm infestations, skin conditions, HIV is also rampant, um, we have also gynecological diseases like STDs and STIs; they are very common in this place. We of course have HIV in adults, diabetics and Hyperstensives. We also see neonatal conditions like this one..., bacterial conjunctivitis, cord sepsis.

Interviewer: What are the major age groups of patients you usually see? Like 10-18 . . .

Respondent: Yeah, diarrheal diseases are common in 0 to 5's and have been more specific in 1 to 5 year olds. That's the same age we get . . . malaria is also common but that's in a specific places like

Nakigaraganga; that's where we get most malaria cases. I did a study around Nakigaranga and we get a lot of malaria both in children and adults, but mostly in children. I did a small study about malaria around this area and it was specifically Kajjansi village and a place called Nakigaranga.

Interviewer: And what was the cause?

Respondent: I think when you look at the demographics of this place, there is a tea farm especially Nakigaranga which is enclosed in the tea farm; there are a lot of mosquitoes within that place.

Interviewer: Okay, tell me about your training in RHD, have you received any specific training in school or after school?

Respondent: Not really, I basically depend on my knowledge in training but I have not any inside training about that heart disease

Interviewer: But during school you had a . . .

Respondent: Yes, and usually we would see heart diseases in wards especially in the medicine wards and they are common in adults. In children, not so much.

Interviewer: So have you received any training about rheumatic heart disease since you graduated?

Respondent: In-service training?

Interviewer: Yes.

Respondent: I have not.

Interviewer: Okay. How many patients with rheumatic heart disease do you usually see? Maybe in a day, week or month here at this health Centre IV?

Respondent: Okay, what I would say is that, most of these conditions come in and we don't recognize them because of the exposure we have had in the field. When I was working in the village, when I would get a patient with a heart problem, it is true he has a heart problem and you know that by the time these patients come to us, they are presenting differently with severe complications. So we just identify then refer to Heart (heart institute).

Interviewer: Are those patients usually in-patients or out-patients?

Respondent: Out patients.

Interviewer: Out patients!

Respondent: When recognized that this patient had heart related conditions, we just refer not even to Entebbe but to the heart institute.

Interviewer: Which means you have not any specific in service training post-graduation. While here you have not had any rheumatic heart disease patients but you have seen some from somewhere else.

Respondent: Somewhere when I used to work in the villages of Wakiso in a place called [inaudible] . . . we could see like three cases.

Interviewer: But you have not seen any here?

Respondent: Not yet.

Interviewer: So what is your understanding of the causes of rheumatic heart disease?

Respondent: Most of them are genital abnormalities but I remember it follows an infection; it could follow tonsillitis caused by a streptococcal resulting into a kidney problem. That's what I remember.

Interviewer: Okay, are you aware of the link between a sore throat and rheumatic heart disease?

Respondent: That one I am aware and I'm a bit conscious about that. So like, if I get a sore throat, I do a physical examination to know it's a sore throat, after that I palpitate around here to check if it was normal. My scope is to identify and I refer. But again in my practice I have never seen like rheumatic fever, rheumatic; those ones I can identify . . . [unclear audio].

Interviewer: So what were you told can be done to prevent rheumatic heart disease?

Respondent: One thing is screening, then getting capacity to the staff on ground about identification of heart diseases. Let all clinicians, in most of these health facilities we are all clinicians actually, you find nursing assistants seeing patients; you find a clinician seeing patients; you find a registered nursing officer and even the midwife seeing patients. So what's missing now is that the health workers should be trained. At least the clinicians should be given inside training, the nursing officers and the enrolled nurses, like what they have done for TB. Each and every staff can recognize TB in children.

Interviewer: So according to you, you think that when the staff or health workers are trained in rheumatic heart disease, it will help?

Respondent: It will be recognized and if it's manageable at our facility, we can manage and if it's not manageable or in complicated form, then we can refer.

Interviewer: What else do you think can be done to prevent the development of rheumatic heart disease?

Respondent: One is early diagnosis and treatment.

Interviewer: Okay, thank you so much. Are there aspects of rheumatic heart management in which you need more training?

Respondent: Yeah, first of all is to be conscious about management of sore throat; if someone can manage it properly, it can prevent the consequences of sore throat. I need to be equipped with more skills in the diagnosis of rheumatic heart disease and maybe some medicines that are sensitive to that condition.

Interviewer: Which means, first of all you need in service training and then you need you need to know more about rheumatic heart disease and its treatment!

Respondent: I will be happy if I know the statistics; how is it? Maybe its distribution too; is it specifically in the areas of central? Is it Wakiso alone or even in districts like Mpigi?

Interviewer: Well basically, due to the prevalence of people who have been coming to UHI, the study has been done in the North was, the main place was Lira, and in the central, we are doing the research in Wakiso and also in the west. So it's not that RHD patients are only in Wakiso but we are just using it as a baseline for the study and in the west we are using Mbarara.

Respondent: Okay.

Interviewer: About the statistics of rheumatic heart disease, the Uganda Heart Institute has done a study and I think it is on the internet. So you can get some of that information from there.

Respondent: Okay.

Interviewer: So, what is your understanding about the long term prognosis of RHD?

Respondent: I think it will be the failure of the valves, deteriorating and leading to, one of them is I think long term . . . if at all they have stepped in and got the rheumatic patient early, it prevents complications which might be fatal to life. Because, if you get heart disease especially in children, it can be fatal to life.

Interviewer: Okay. According to you, do you think the long term prognosis is good or bad?

Respondent: It's poor.

Interviewer: Okay, tell me about your encounters with patients with rheumatic heart disease; do you recall your last patient with rheumatic heart disease?

Respondent: Yeah, I think it was 6 years back. Usually they appear with complications; just your child might fail . . . [unclear audio] but on close examination, to rule out whether or not the child is just mal-nourished child, when you palpitate the chest you find out that the problem is with the heart.

Interviewer: How did the last patient you saw present?

Respondent: Um, wasted; the patient was wasted and looked very weak, and I remember the mother told me in Luganda that "when she is playing, she can't play very well. She plays just a little then rests." So according to my teaching, I just knew that this is likely to be a heart issue.

Interviewer: So what is the average age of your rheumatic heart patients? Okay those ones you have seen. You told me you have not seen any here but about the ones you have seen?

Respondent: They are below seven years.

Interviewer: Below 7 years! And they are not working?

Respondent: They are not working

Interviewer: They are students? Because I need to know whether or not they are working; are they in school?

Respondent: They were out of school; they had this problem for a long period of time.

Interviewer: Okay, so they were out of school!

Respondent: Yeah.

Interviewer: Okay. So, are they generally aware of a link between sore throat, acute rheumatic fever and rheumatic heart disease?

Respondent: They are not aware.

Interviewer: They are not aware!

Respondent: To be honest even some of the health workers are not aware, and that is why I would plead for in-service training because we take tonsillitis simple and that it can be managed over the counter but, it is very common. Because even here, there was one time when I asked one of the staff, “are you aware that a sore throat can lead to a heart disease?” and she said, “Are you sure?” So even the management has issues with sore throat because even the gadgets we use in examining the sore throat don’t exist in these health facilities; the tongue depressors, touches, facilities don’t have them. The other hindering factor is a lot of patients; you can reach them but you just fail to examine them and when some of these conditions are not examined, these patients can go back. Whoever comes, our only impression here is malaria.

Interviewer: Which means that first of all, the patients are not aware of the link, the health workers are not aware, and then the health workers would have been learned but they don’t have enough time!

Respondent: Time with the patients especially for examination of patients, and then the equipment we use, tools like the tongue depressor. So there is a knowledge gap.

Interviewer: What sort of symptoms do these patients usually describe?

Respondent: in the initial stages in the children, its pain with swallowing and mostly parents say, “the child doesn’t eat” and when you check you find that she has some temperature and also has some irritation in the throat. After that, you can examine and tell.

Interviewer: Are these patients usually good with adherence to treatment or they are not?

Respondent: In children, adherence is determined by the preparation of medicine. Even right now, you just have Amoxyl to prescribe in its actual format and you are giving it to a child who is below 5 years! So, you have to instruct the mother to first open the capsule and then give. So even the preparations can affect adherence. So that is also another challenge, and majority of our patients can rarely take the full course of medicine for 7 or 5 days.

Interviewer: Rarely!

Respondent: rarely.

Interviewer: so this means they don’t complete the full course of medicine! Is it because the drugs are not there or?

Respondent: Absence of drugs is also another issue. Then the other gap is overall health seeking behavior; our patients usually come here after three days when the cough has been there for 4 days! So there is that poor health seeking behavior and the lack of essential drugs at the facility.

Interviewer: Okay. So what sort of barriers do they commonly state to get the care they need?

Respondent: I think that one of the problems could be that, our patients believe that when I go to the facility, you know they don’t come here to get information but to get medicine. So when they come here and we don’t have medicines, they’d rather stay away because they believe, “there is no medicine there” not knowing that seeing a trained health professional makes them get a proper diagnosis and maybe they can buy medicines. But for them they usually say “what am I going to do there when there are no drugs!” Some of us have sat with them during interviews and when we ask them what they have gained in health facilities they say, “Nothing!” and yet someone has gone through the lab and someone has seen you. So

then you start explaining; at least you have gone to the lab and found that the patient has no malaria, then you give Amoxyl for three weeks, and then you compare your services with the private facilities. You say, “you have not paid for consultation here, you have gone to the lab and you have not paid for services in the lab and at least you know where the problem could be.” So patients come here to get medicine and if you don’t have medicine, actually there was one patient who told me (arrogantly), “Why don’t you just close this facility?” So people come to government facilities, they come here to get medicine. They are not aware that our presence here, that information is knowledge.

Interviewer: Okay, so what sort of barriers do you perceive these patients face in getting the care they need?

Respondent: I think one of them is lack of information.

Interviewer: The patients themselves?

Respondent: yes, and the poor health seeking behavior, then they know little about their health. Those are some of the barriers the patients face. Then for us here, we are understaffed of course, we don’t have logistics to use, we are limited in areas of diagnosis for some of these conditions. Personally, I trained 15 years back, so when you ask about rheumatic heart disease, only that I have been a senior officer who practices medicine, otherwise most of the senior officers aren’t practicing administration.

Interviewer: That’s right. So when you are senior officer practicing medicine, you are different from one in administration because the one part in medicine is seeing patients and the other is not.

Respondent: He is ever in meetings. Some of us refused to go and attend the meetings just because there is no way you can leave the patients unattended to. Besides, administration alone is enough for you because you will ever be moving up and down, and as a senior clinician, you . . . [unclear audio]. So we are lacking CMEs about this condition, so the knowledge gap comes in.

Interviewer: Okay. So, we are going to talk about the local health system barriers; like in Wakiso district, what are some of the barriers do you have from administration and the leadership at the district, or what are the enablers or what works for you in this local health system?

Respondent: Yeah, one is that the structures are existing where we can see patients. Another one is that at the moment, issues of patients’ privacy are being addressed because we are having those structures being put in place. In some areas besides rheumatic heart disease, we are capacitated with knowledge of these conditions. Like in TB, at least each and every staff can recognize TB. In areas of HIV, majority of the staff is availed information in HIV care, circumcision and the like. But in regards to rheumatic heart disease, it could be news to some of the staffs. So some areas are being addressed. Of course infrastructure is some of the hindrances; we are not residents at this facility, so transport issues come in. like, I stay in Ntinda-Kiwatule, so the transport is much. However, if the health worker can be accommodated at the health facility, punctuality could be worked on. It would be so easy because someone could come directly from his house and come to the OPD.

Interviewer: Which means the issue of housing around the health facility is a barrier!

Respondent: Yes. Then um, if there are heart diseases, first of all that commends for investigations. Some of these health facilities, besides the clinical virtue that we possess, I would be very comfortable to have some heart investigations that could be in my catchment area . . . [Audio cut short]

[Audio resumes] technical support supervisions right away from the ministry, from the district and from health sub districts

Interviewer: There's lack of technical supervision!

Respondent: Yes.

Interviewer: Okay. Wow, that's good. Tell me about the funding of health care in general and specifically for rheumatic heart disease. How is the funding here? Are you aware about any information about funding?

Respondent: Well the government is trying to address those; it has tried to address its financial constraints in various angles.

Interviewer: Like?

Respondent: Like PHC comes at least every quarter.

Interviewer: What is PHC?

Respondent: Primary Health Care funds. It's little but it has been coming. There are some days it delays but it has been coming. That one has somehow improved the infrastructures, the sundries and maybe maintaining the health facility cleanliness and paying some allowances, because I believe if we make integrated outreaches, the government helps training for rheumatic heart disease within the community because if every child is going for immunization it is recognized, but that comes back to the knowledge gap because the health worker will go there just focusing on immunization but an integrated is there to identify and then refer to the health facility or to . . . in that case the health worker should have a referral form. But right now there has been RBF funding.

Interviewer: RBF is?

Respondent: It is Result-based Funds. That one is also likely to help make the staffs available at the health facility. Two; some of the money can be partitioned to . . . [unclear audio]

Interviewer: Okay, tell me about the numbers and qualifications; are the health worker numbers enough and are they qualified? Are they able to see patients and provide proper quality of care to these patients?

Respondent: Yeah. What the health workers need is in-service training to address those conditions. The number here is optimum; it is relatively enough as compared to other health facilities which is a challenge; you find that you are 8 people working at a health center III and yet according to the Ministry, you are supposed to be around 15 staff. So here, we are about twenty because they made this health facility a Health Center IV but the structure of cadres here is within a Health Center III.

Interviewer: So tell me about your health information or medical record system, how do you do it?

Respondent: That one is improving especially in areas of HIV care and circumcision; they have been a drastic improvement in data quality management specifically in HIV. Recently stores have also improved; the management has also introduced a systems called RX Solutions which has also come on board and I have seen it on ground being applied.

Interviewer: What about the patients at the facility? Because I have heard that HIV, stores . . . but what about the patients? How is their record keeping? Where do you keep your registers? In-patients and outpatients?

Respondent: Yes we have. We get registers straight from National Medical Store and others we get them from IPs.

Interviewer: What is IP?

Respondent: Implementing Partners. Actually of recent, the ministry, I think is in good relationship with IP Mildmay where they recruit . . . , so its most of the required data improvement tools to see that there in-patient registers, stock cards and access them.

Interviewer: Do you have specific registers, for example registers for Acute Rheumatic Fever and Rheumatic Heart Disease?

Respondent: No, there is a register which combines all medical conditions with some specific areas of palliative care, TB. There has been upgrading of this register; at least every 2 years it is upgraded, so maybe next year it is this one to be upgraded.

Interviewer: So you don't have an electronic system whereby you keep your data?

Respondent: Hmm! No

Interviewer: Okay. So do you have any guidelines and protocols for rheumatic heart disease care or a referral path such that whenever you receive a patient here, you are able to refer them to the necessary Centre?

Respondent: We use a general one because . . .

Interviewer: The general what?

Respondent: Referral note, where you write the diagnosis, which may not even be a diagnosis but just an impression and indicative of the station where you are and where you are referring. That is the referral note, the referral booklets from NMS that are always provided as we pick drugs.

Interviewer: What about the guidelines and protocols, do you have them?

Respondent: We just use the UCG, that's our guideline

Interviewer: What is UCG?

Respondent: Uganda Clinical Guidelines.

Interviewer: Okay. It's that general one that works on all patients, you don't have any for specific . . . ?

Respondent: No, and that is where TB has gone far (improved) because for it they provide guidelines and protocols for management and about care, so if we could get like working guides, it could work, just the way you see the one for TB.

Interviewer: Okay. Thank you so much. Umm, tell me the local health system enablers? How has this health care system or how has the administration made work easy for you to diagnose and see patients? How has the system enabled you?

Respondent: Through trainings and workshops, like we did some of this IMCI courses after I qualified, personally I have done palliative care; I have seen some heart diseases at Mulago Hospital. So it's in-service training. Individually, the passion you have for patients drives you, like you feel "I have to go back and read about this condition." Right now, you have triggered me to go back and read about rheumatic heart disease.

Interviewer: Okay, that's good. So generally, do you think these patients . . . I am asking about the patient perception outcome; do you think patients get the care they need or not?

Respondent: About rheumatic heart disease?

Interviewer: Yes, about rheumatic heart disease especially surgery.

Respondent: They don't.

Interviewer: Why?

Respondent: Umm, most of these, by the time you are admitted at Mulago for surgery, first all we don't show our patients the diagnosis, so they may think that maybe it's witchcraft. So the perception of the illness, three of us as health workers don't tell our patients the true diagnosis and by the time they recognize that maybe this is a heart problem, these people have spent lots and lots of money. Even in public facilities, you have to pay there some money for ECG-ECHO.

Interviewer: Okay. So, tell me about patient safety.

Respondent: Then the other thing is health education; should anyone get a heart disease, it means death. So health education has a gap and yet some of these conditions are managed. People believe that some of these conditions are not managed. Actually the perception is that you have to get surgery outside Uganda.

Interviewer: So according to you, most of these patients don't get the care they need because first of all they are not properly educated by us health workers!

Respondent: Yes, by the health workers and they also don't know the real clinical picture of rheumatic heart disease.

Interviewer: Okay. Talk about patient safety and quality of care concern; do you think that when these patients come to us as health workers they get the proper quality of care and everything they need? For example if a patient came here, do you think they would get the care they would have needed for example in this health care setting?

Respondent: When you talk about quality, the quality of health care in government facilities is fair, that's what I can say. It's not good, not bad, but fair; that's what I can say.

Interviewer: It's not good or bad but it's just fair!

Respondent: yes

Interviewer: What about the patients; are the patients safe with the health workers? Or should I paraphrase it; has there been any preventable death in this hospital?

Respondent: Maybe, depending on the condition.

Interviewer: Depending on the condition! Okay. Do you think patients are dying in the community without presenting to the hospital for care?

Respondent: Yes.

Interviewer: Why do you think?

Respondent: First of all it is their understanding of the illnesses is very important. The [unclear word] is many saying that maybe this is witchcraft and you know people still believe in using our traditional medicines before coming to the health facility. The percentage, is it 70%? So they first use traditional herbs before coming to the health facility. So the perception of the illness also matters a lot. Then another thing is that we are starting from ground; most of the health workers don't go in the field to identify, health-educate, there is lack of information for us here to get facilitation and then move down. Right now why are we still suffering from malaria and yet we know the cause? Even the environment alone is . . . [inaudible word].

Interviewer: So according to you the reason why patients in the community die is because we as health workers have not gone to that level; the village level to disseminate information!

Respondent: Yes

Interviewer: So they also lack that information so they end up not coming to seek care!

Respondent: Yes

Interviewer: Does that come back to the poor health seeking behavior you were talking about?

Respondent: One of them is the poor health seeking behavior and another one is facilitation of the health staff to go down.

Interviewer: so, the last question; in your opinion, what are the two most important things ministry of health should do to improve health comes in patient care?

Respondent: One of them is to equip the health staff and health workers on the ground with knowledge about rheumatic heart disease. Another one is remuneration of health workers; we are not well remunerated in terms of money. Then they should also improve the infrastructure which goes up to the health worker, and the other thing are the logistics.

Interviewer: Okay, thank you so much

Respondent: you are welcome

Interviewer: thank you so much for your time. That was quite . . . [recorder stopped]

Participant ID	HW 005 -Wakiso
Date	Mar/2019

NURSE

KAJJANSI

VENUE: CLINICIAN ROOM

INTERVIEWER:

Interviewer: So we are at Kajjansi health Centre IV in the clinicians' office and we want to know . . . I am with a health worker here and we are having a discussion on building a case to invest in Rheumatic heart disease in a limited resource setting. Now tell me about yourself; how old are you?

Respondent: I am [REDACTED] years old.

Interviewer: Okay, thank you. Tell me about your qualifications and where you trained from.

Respondent: As I have said, I am [REDACTED].

Interviewer: That's where you qualified from!

Respondent: Yes.

Interviewer: When did you qualify?

Respondent: In [REDACTED].

Interviewer: Okay. So how long have you been qualified?

Respondent: Since [REDACTED].

Interviewer: is that [REDACTED] years?

Respondent: it's like [REDACTED] something years.

Interviewer: Okay. So how long have you been working here at Kajjansi Health Centre IV?

Respondent: Its [REDACTED] years.

Interviewer: And you are working in OPD?

Respondent: Yes.

Interviewer: How long have you been [REDACTED]?

Respondent: [REDACTED] years.

Interviewer: That's good. As a nurse, tell me about the demographics of the patients you see here; the patients you see in your practice and the common illnesses you treat, their age group . . .

Respondent: We treat the under 5s; they are many. Then the youths and elderly. We see all the age groups.

Interviewer: Okay, so what kind of common illnesses do you usually see?

Respondent: We normally have the respiratory tract infections, malaria, those with wounds, diabetes & hypertension, and those with skin diseases.

Interviewer: So in the age groups, do you usually see the young from 0-5 years, 10-18 and above? What kind of patients do you see? What is the age group that you mostly see?

Respondent: Most of them are children; the under 5s.

Interviewer: So tell me about your training in Rheumatic Heart Disease; have you received any specific training during school?

Respondent: No.

Interviewer: Even during school!

Respondent: No.

Interviewer: When you were in school they never taught anything about Rheumatic Heart Disease?

Respondent: I don't remember.

Interviewer: Okay. What about after school; did you receive any training after graduation?

Respondent: No.

Interviewer: So you have no idea about Rheumatic Heart Disease?

Respondent: No.

Interviewer: Okay. How many patients of Rheumatic Heart Disease do you often see here in the OPD clinic, maybe in a week or a month?

Respondent: Since we don't have the investigations, we can't investigate and say that this one is having a Rheumatic Heart Disease.

Interviewer: So that means you don't see them here?

Respondent: We don't.

Interviewer: You don't! So if a patient came here with Acute Rheumatic Fever which leads to Rheumatic Heart Disease, do you think you would be able to know?

Respondent: No, we can't differentiate them from these other . . . [coughs]

Interviewer: You can't differentiate them from the other patients?

Respondent: Yes.

Interviewer: So what is your understanding of the causes of rheumatic disease?

Respondent: [Silence]

Interviewer: There are no wrong or right answers.

Respondent: [Giggles]

Interviewer: So just tell me what you know.

Respondent: Maybe one is having heart diseases.

Interviewer: So heart diseases causing Rheumatic Heart Disease?

Respondent: Yes.

Interviewer: Okay, anything else?

Respondent: No

Interviewer: Okay. Are you aware of a link between rheumatic heart disease and sore throat?

Respondent: No.

Interviewer: okay. So what were you taught can be done to prevent or treat Rheumatic Heart Disease?

Respondent: Nothing.

Interviewer: so are there any aspects of rheumatic heart disease management in which you think you need more training?

Respondent: [no response]

Interviewer: Okay like you said you have not received any training both at school and out of school (after graduation), but currently you are the in-charge of OPD and you see very many patients in a day. So do you think there's any aspect of Rheumatic Heart Disease management in which you need more training?

Respondent: I need training in all; the signs and symptoms, management, how it presents and the prevention.

Interviewer: So you need training in all of it.

Respondent: Yes, I need training in all of the disease.

Interviewer: So what is your understanding about the long term prognosis of RHD?

Respondent: Long prognosis?

Interviewer: Long term prognosis.

Respondent: That it takes time to heal.

Interviewer: okay, it takes time to heal!

Respondent: Yes.

Interviewer: So do you think it heals quickly or it takes long to heal?

Respondent: It takes long.

Interviewer: it takes long to heal! Do you think it ever heals at all or it doesn't?

Respondent: I think it doesn't heal.

Interviewer: Okay. Thank you so much. So the next question; tell me about your encounters with a Rheumatic Heart Disease patient. You have you been an in-charge at OPD for 8 years, have you encountered any cases or patient with Rheumatic Heart Disease?

Respondent: I think there's a patient whose father normally comes here; he comes for Benzathine. I wonder if that was Rheumatic Heart Disease!

Interviewer: How many times does the father come here?

Respondent: He doesn't come with the patient but he normally comes for the Benzathine that they prescribed from Mulago. When they don't have it, they come here and if we have them, we give them.

Interviewer: And you inject them?

Respondent: Yes.

Interviewer: What is the age of the patient? Because my next question would be; what is the average age of your Rheumatic Heart Disease patients? Are they working or not, are they in school or not?

Respondent: Personally, I have never seen that patient because the father usually comes and picks the drugs if we have them.

Interviewer: So who injects the patient?

Respondent: They have a special nurse to inject at a nearby place.

Interviewer: So the father comes here at the health Centre IV.

Respondent: Yes, with the prescription from Mulago (Hospital). He tells us "if you have these drugs, you can give me and if you don't have, I go and buy."

Interviewer: Then he takes it to the nearby clinic at home?

Respondent: Yes, that's the only one I remember.

Interviewer: So you have not been in touch with a Rheumatic Heart Disease patient for all the time you have been here?

Respondent: No.

Interviewer: That patient whose father you have seen, are they aware of the link between sore throat, Acute Rheumatic Fever and Rheumatic Heart Disease?

Respondent: I don't know.

Interviewer: You don't know.

Respondent: Yes.

Interviewer: Okay. What sort of symptoms does that man describe that the patient presents?

Respondent: Hmm, he didn't even describe.

Interviewer: He didn't describe, he just only came for medicine only?

Respondent: Yes.

Interviewer: So which means you don't know the kind of symptoms these patients present with?

Respondent: No.

Interviewer: Wow! So now you told me that's the only case you know.

Respondent: Yes.

Interviewer: Then that's the only case I am going to ask you about. About adherence and follow up, how often does that father come here to get the Benzathine?

Respondent: He can take a month without coming here. I think when he goes to Mulago and gets, he can take some time without coming here.

Interviewer: Okay. So what sort of barriers do those patients commonly state to getting the care they need?

Respondent: The barrier to get treatment?

Interviewer: Yes.

Respondent: Sometimes the drugs are out of stock.

Interviewer: That's one of the major barriers, anything else?

Respondent: The transport.

Interviewer: Transport from where to where?

Respondent: To where to get the treatment.

Interviewer: Okay. Anything else?

Respondent: No.

Interviewer: So what sort of barriers do you perceive these patients commonly face? As a health worker what kind of barriers do you perceive these patients face in getting the care they need?

Respondent: They take long without being diagnosed and then the disease progresses.

Interviewer: Okay.

Respondent: Because the health workers lack information about those diseases.

Interviewer: So that's the barrier; the health workers don't have enough information about the disease, so it becomes barrier to these patients when they come in for care?

Respondent: Yeah.

Interviewer: Okay.

Respondent: Because if the patient comes here with this disease and I personally don't know the signs and symptoms, I just continue giving antibiotics. Then it takes long to be diagnosed that he's having a heart disease.

Interviewer: So I am going to ask you about the local health system barriers, administrative wise and leadership wise in the district.

Respondent: Administrative?

Interviewer: Yes, in relation to management and treatment of rheumatic heart disease. Do you think everything is working in accordance to what would be needed to provide health care to these patients at this health Centre? Administrative wise and leadership wise; does the district provide the necessary things to provide health care to those Rheumatic Heart Disease patients?

Respondent: No.

Interviewer: So according to you, what is the health system barrier according to the leadership and administration at the district?

Respondent: Lack of diagnostic equipment like the x-ray; we don't have them. Most of the health units don't have those diagnostic equipment.

Interviewer: What about health care funding in general and particularly in RHD? Are you aware of the funding in this unit?

Respondent: No, I am not.

Interviewer: So tell me about the health care workers you have here; their numbers, qualifications, are they able to wait for the patients and provide the proper quality of care?

Respondent: They can provide but most of the time, sometimes the drugs are out of stock and we don't have them.

Interviewer: Anything else?

Respondent: They lack information.

Interviewer: The health workers lack information.

Respondent: They lack adequate information about those RHD diseases.

Interviewer: Okay. What about medication; when the patients come here, for example, you have talked about that man. Do you have medications like Benzathine penicillin, anti-coagulants and heart failure drugs?

Respondent: No, we don't have them. We don't have most of them.

Interviewer: You don't have them! What about the diagnostics?

Respondent: No.

Interviewer: You don't have?

Respondent: Yes.

Interviewer: Okay, so tell me about health information or medical records systems; how do you keep your information? How is your health keeping at the unit?

Respondent: We have the Health Information Officer who keeps the out-patients books. He is the one who keeps them.

Interviewer: What about integration between all units; do you have an in- patient unit around here?

Respondent: In maternity.

Interviewer: Only maternity?

Respondent: Yes. At OPD we don't have in-patients.

Interviewer: Okay. So the record keeping at maternity is different from all the other units?

Respondent: Yes.

Interviewer: Do you have specific registers for specific conditions for example, a register for Acute Rheumatic Fever?

Respondent: No, we don't have. They are combined.

Interviewer: So how has the local health system enabled your work to become easier to management of patient care?

Respondent: hmm, now how?

Interviewer: Now like in this health system, what motivates you to leave home and come to work? What has the health system made easier for you to be able to provide patients with care?

Respondent: salary.

Interviewer: Only salary?

Respondent: When the drugs are there, I am comfortable.

Interviewer: Okay.

Respondent: But when the drugs are not there, I say, "Go and buy! Go and buy" for everything. It is demotivating.

Interviewer: So if the drugs are there, it motivates you to do your work and when you are paid on time, it also enables you to do your work.

Respondent: Yes.

Interviewer: Okay. So perception of patient outcomes; generally, do you think these patients get the care they need or not?

Respondent: Sometimes, but when things are out of stock, they don't.

Interviewer: How often do you have stock outs?

Respondent: We can even take a month or three weeks.

Interviewer: About patient safety and quality of care concerns, have you had preventable deaths here at the hospital? A situation where by this patient came here sick but you feel as health worker if you did what you were needed to do, you would have prevented this patient from dying. Have you ever had that scenario?

Respondent: No.

Interviewer: You have not! Do you think patients are dying in the community without presenting to the hospital?

Respondent: They die.

Interviewer: Why?

Respondent: Some can stay in those traditional healers, some may not be having transport to take them to hospitals. So they die in the community.

Interviewer: So in your opinion, what are the most important things Ministry Of Health should do to improve patient outcomes?

Respondent: Providing enough drugs to the hospitals, providing those diagnostic equipment.

Interviewer: Okay. Just that . . .

Respondent: And improving referrals like providing ambulances to health units.

Interviewer: Okay. What about training of health workers?

Respondent: And training of health workers.

Interviewer: Okay. Anything else?

Respondent: We talked about drugs?

Interviewer: Yes.

Respondent: Only those.

Interviewer: So we talked about the drugs, ambulances, diagnostic equipment and you also talked about referrals.

Respondent: Yes.

Interviewer: Okay. Thank you so much nurse for your time.

Respondent: you are welcome.

PARTICIPANT ID	NURSE – HW006 - Wakiso
DATE	March 2019
VENUE	ENTEBBE HOSPITAL WAKISO DISTRICT
AGE	■
INTERVIEWER	

Interviewer: Okay, this is a study to determine, how to provide better health care for Rheumatic Heart Disease and there are no right or wrong answers, and please be frank and share your opinions. The data we gather is confidential and we don't need to put your names. I will not link your identity to any of your comments in any of the reports we produce, okay? Okay, tell me about yourself; how old are you?

Respondent: ■ years old.

Interviewer: You are ■ years! And by the way which office are we seated in right now?

Respondent: OPD.

Interviewer: Yes OPD, but this specific room?

Respondent: This is a consultant room.

Interviewer: So we are in the consultant room number 5! Okay, that's good, so you're ■ years old?

Respondent: Yes.

Interviewer: Okay, tell me about your qualifications, about your training, where you trained from and whether nursing school or medical school.

Respondent: I am an ■.

Interviewer: Okay, when did you qualify?

Respondent: I qualified in ■

Interviewer: So how long have you been qualified?

Respondent: It's like ■ years.

Interviewer: From ■?

Respondent: Yes.

Interviewer: How long have you been working at Entebbe Regional Hospital, or Entebbe General Hospital?

Respondent: Since [REDACTED].

Interviewer: That's how many years now?

Respondent: They are [REDACTED] years.

Interviewer: So you have been working here for [REDACTED] years, you qualified in [REDACTED] and you are [REDACTED]
[REDACTED]

Respondent: Yes.

Interviewer: Okay, Tell me about the demographics of the patients in your practice or the common illnesses that are usually treated here.

Respondent: Cough, flu, malaria, hypertension, diabetes and TB.

Interviewer: Those are the main elements that you usually see!

Respondent: Yes.

Interviewer: Tell me about their age groups.

Respondent: For malaria?

Interviewer: For all of them. Which one do you mainly see? Are they young? They are for which age group?

Respondent: We get all ages because this is OPD.

Interviewer: Okay, for example malaria, do you always see the young ones? Do you usually see the teenagers or elder groups?

Respondent: Malaria; mainly the young ones.

Interviewer: What about their conditions!

Respondent: The conditions like cough and flu, I mean the young ones.

Interviewer: Okay.

Respondent: Even sometimes we get these incomplete abortions, but cough and flu are the most common, and typhoid by the way. I had forgotten typhoid.

Interviewer: Okay, thank you so much. So tell me about your training on Rheumatic Heart Disease; have you received any specific training during school?

Respondent: Yes.

Interviewer: So what did they tell you Rheumatic Heart Disease was?

Respondent: Huh! Rheumatic Disease; this is the disease that occurs . . . I don't remember very well but it's the disease that occurs when someone has over stayed with . . . Okay, someone who usually gets cough, flu and such; that's what I remember. [Laughs]

Interviewer: Okay, have you received any training since you graduated about Rheumatic Heart Disease?

Respondent: No.

Interviewer: You have not! Okay, so don't you do CMEs around here?

Respondent: We do, but they're always on Tuesdays.

Interviewer: So among the so CMEs; do you have any about RHD?

Respondent: The cause of RHD?

Interviewer: Yes about Rheumatic Heart Disease!

Respondent: No, not yet.

Interviewer: Okay. So how many patients of Rheumatic Heart Disease do you often see like in a day, week or month?

Respondent: What can I say! We rarely get that condition being that someone is diagnosed with Rheumatic fever. Huh, to me it's a rare disease. I think it's because of poor diagnosis, I don't know, but since my training I haven't seen anyone and they have never told me anything like that person has Rheumatic Heart Disease, no.

Interviewer: So, um, these patients, so you have not seen any?

Respondent: No.

Interviewer: Not even in this out-patient department?

Respondent: I haven't seen any. For sure maybe it's because of poor diagnosis, but I haven't seen someone that it is written that the diagnosis is Rheumatic Heart Disease.

Interviewer: Now tell me about your understanding about the causes of Rheumatic Heart Disease; how do you understand Rheumatic Heart Disease and what are its causes? How do you understand it as a healthy worker?

Respondent: Huh! I think, it's an inflammation, it's a complication that comes in when someone has over stayed with cough, flu and sore throat. What I can say is that it moves; when the cough, flu and sore throat over . . .

Interviewer: When they over?

Respondent: Okay let's simplify it; if someone gets cough and flu for so long and keeps on getting those diseases, has signs and symptoms of those diseases it . . . [stammers]

Interviewer: Explain it in a simpler way even in Luganda.

Respondent: Okay, the outcome, not even the outcome but it generates to the heart, I mean the inflammation, and then you find when someone has ended up getting Rheumatic Heart Disease.

Interviewer: Okay, so what do you think is the cause? What do you think causes?

Respondent: The cause of Rheumatic Heart Disease?

Interviewer: Yes.

Respondent: Bacterial infections.

Interviewer: What kind of bacterial infections?

Respondent: Am not sure of it.

Interviewer: Okay thank you. So are you aware of a link between a sore throat and Rheumatic Heart Disease?

Respondent: Yes, sore throat and Rheumatic Heart Disease.

Interviewer: How?

Respondent: Explaining it is not easy.

Interviewer: No, you speak in a lay man's language. You said you are aware of the link, isn't it?

Respondent: Yes.

Interviewer: So how do you understand that link between sore throat and Rheumatic heart disease?

Respondent: The pharynges . . . [stammers] I just have an idea but am trying to connect. I have failed to connect very well but what I know is there is a link.

Interviewer: Okay, you are aware there is a link!

Respondent: Yes.

Interviewer: Okay, what were you told can be done to prevent Rheumatic Heart Disease?

Respondent: The quick diagnosis of it; treatment for these Common diseases like flu and cough. When they are easily treated, okay, when they are treated early I think that Rheumatic Heart Disease can be prevented.

Interviewer: Earlier on we were talking about prevention, what were you taught can be done to treat Rheumatic Heart Disease?

Respondent: I remember they told us that Penicillins are the best treatment.

Interviewer: Okay, thank you so much. Are there any aspects of Rheumatic Heart Disease management in which you think you need more training?

Respondent: Actually we need training on it because, for sure, for me since I trained . . . that's why I have forgotten everything. We need everything to be trained; the causes, the treatment and how to diagnose it very fast,

Interviewer: Okay, so which means that you need training!

Respondent: Yes, we need to know more about it for at least easy diagnosis

Interviewer: So which means that you need to know more about this, anything else?

Respondent: The causes, prevention and treatment if it has occurred

Interviewer: Anything else?

Respondent: um, even the whole management and nursing care.

Interviewer: So what is your understanding about the long term prognosis of Rheumatic Heart Disease?

Respondent: The what?

Interviewer: What is your understanding about the long term prognosis of a patient with Rheumatic Heart Disease?

Respondent: It can lead to the heart failure.

Interviewer: Anything else?

Respondent: It also leads to difficulty in breathing because of the pain of the heart.

Interviewer: Okay. So according to you, is the long term prognosis of Rheumatic Heart Disease a good or bad one? How do you understand it?

Respondent: Long term what?

Interviewer: Yes, long term prognosis.

Respondent: It is bad.

Interviewer: Why is it bad?

Respondent: Long term prognosis, it can be misdiagnosed on someone, leading to poor treatment or adherence to the patient.

Interviewer: So you are saying that according to you the long term prognosis of RHD is bad!

Respondent: Yes

Interviewer: Because you're saying that some patients don't adhere to treatment!

Respondent: Yes.

Interviewer: And you also talked about diagnosis, is there anything else that you talked about?

Respondent: No.

Interviewer: Okay, so tell me about your encounters with patients with Rheumatic heart disease. Do you recall the last patient you saw with Rheumatic Heart Disease and can you briefly summarize that visit?

Respondent: Apart from studying it, I haven't seen any patient with it.

Interviewer: Apart from studying Rheumatic Heart Disease you have not seen a patient with it!

Respondent: Yes.

Interviewer: Even here in the outpatient department?

Respondent: I haven't seen.

Interviewer: Wow! So what is the average age? You said you have not seen any patients the five years you have been here?

Respondent: I haven't seen, and that's why I was saying whether it could be due to poor diagnosis. Someone can be having it and they diagnosed another thing yet it's Rheumatic Heart Disease.

Interviewer: So what do you think is the average age of Rheumatic Heart Disease patients?

Respondent: The average?

Interviewer: Yes.

Respondent: 45.

Interviewer: 45years. Okay, are they usually working or not?

Respondent: Working?

Interviewer: Those patients; are they usually working or not?

Respondent: Working

Interviewer: Do you think those patients are generally aware of the link between sore throat, Acute Rheumatic Fever and Rheumatic Heart Disease?

Respondent: They are not aware. The patients themselves?

Interviewer: Yes.

Respondent: For one to know that I am suffering from this, or that it's a complication of cough and what?

Interviewer: Yes.

Respondent: They are not aware.

Interviewer: So what sort of symptoms do they describe? Those patients of Rheumatic Heart Disease.

Respondent: Apart from . . . well according to what I studied, they present with fever, cough, flu, sore throat and a bit of difficulty in breathing and chest pain,

Interviewer: So you said you studied but you haven't seen any!

Respondent: I haven't seen, that's the little I remember.

Interviewer: About the follow-up and the adherence to treatment, you don't know because you have not seen any of them?

Respondent: Yes. From the school I haven't got that chance at least.

Interviewer: Because my next question was; what sort of barriers they usually state in getting the care they need? But you have told me you have not seen any!

Respondent: I haven't seen.

Interviewer: So now you as healthy worker, what sort of barriers do you perceive these patients face in getting care they need?

Respondent: Barriers; poverty because you can find that the treatment may be . . . I am just talking because I haven't seen one, but you find someone has told you they will be getting such a

treatment for such a time and that patient has to pay that money, so you end up staying, or she can get for like three days and then he drops out.

Interviewer: Okay, anything else.

Respondent: Barriers?

Interviewer: What sort of barriers do you perceive these patients get in getting the care they need?

Respondent: These patients, they know that I have Rheumatic Heart Disease but the barriers they face.

Interviewer: What barriers do they face?

Respondent: um, I think some patients, the ones I have seen that get medicine, some of them they don't want to take medicine, like men. For the men, they take just one day and you find that there are poorly adhering to their treatment. So it's according to them that treatment is not an issue; when someone gets some small improvement he just drops out from the treatment without a big reason. And some Penicillins are QID; you can find someone, the timing, you find someone has got treatment and needs to get treatment at night but if that person is not in the hospital, he can fail to get themselves to the hospital to get that night treatment.

Interviewer: So that becomes a barrier in a way that patients take the treatment, you said QID!

Respondent: That's 4 times a day

Interviewer: Which means that you mean that . . .

Respondent: It can mean many times, because most of the Penicillins are eight hourly, I mean six hourly. So that patient can fail to fulfil the time even if the treatment is there because of the long time. If it was already once a day, that one would be okay.

Interviewer: Okay, thank you very much. So we are going to talk about the local health system barriers; tell me about administration and leadership in Wakiso district. What barriers do you usually face as a health worker in regard to administration and leadership, or in providing care to the patients?

Respondent: [laughs] overwork; okay, overloaded

Interviewer: Overloaded with what?

Respondent: Now here in the OPD, we are very few. You have seen the number of patients we are having, but we are few! We are like, let me count; we are like five! Yes, managing day and evening.

Interviewer: So that means that . . .

Respondent: We also get tired and we end up not giving what we are supposed to give to the patient. Then another thing, yes there are CME's but there are courses which are rare; instead of taking a nurse to study that, let me say diabetes or Rheumatic Heart Disease, we who are on ground I think we are supposed to be trained to know what we supposed to do. But you can find someone they have taken to study about Rheumatic Heart Disease works in theatre or in administration, someone who is not related at least to patients! That's the person who goes to such courses yet they leave people who are supposed to go for that. Because, to me, if I was a leader I can say, "these people working on a ward are supposed to study diabetes, this and this have to go," instead of calling someone from a different department, because to me it's not good. That's why people say [in agitation], "Argh!" They take it easy, but even if someone comes and says that they are going to teach about, let's say malaria, I may hear someone from records going to teach malaria! You just say to yourself, "Uh, after all I studied malaria from training school," so you leave them.

Interviewer: So which means that's an administrative barrier for you to provide best health care!

Respondent: Yes, because you never know that person would have given you the new guidelines on such a disease, but being like, now this is someone who works in records; how can he teach me about malaria? You just leave it at that.

Interviewer: So you leave it at that!

Respondent: Yes, then another thing they increased money.

Interviewer: Money for?

Respondent: For nurses. Okay, for medical workers. They added some money but on ground people are saying, "Why is it that the registered (ones) were given good money and they left the enrolled (ones)?" They just added 100,000/= on the money we (enrolled ones) were getting, so that thing also when it comes to someone who doesn't have that heart of patients, they can just say, "Argh, those ones received money!" For us we are here overworked but now how many white people have you seen in this OPD?

Interviewer: Apart from this one!

Respondent: Yes, so with those people, if you don't have heart, they end up saying, "I am going to do the little I can" without putting much effort.

Interviewer: Okay. So tell me about the funding for health care in general and about Rheumatic Heart Disease if you are aware of any. Do you have funding in the hospital here?

Respondent: The funding?!

Interviewer: Like the funds that come from the district and government. Funding for health care in general and Rheumatic Heart Disease.

Respondent: Of course the funding for Rheumatic Heart Disease, I haven't heard anything. For other things, they fund.

Interviewer: Other things like what?

Respondent: I heard of malaria but I don't remember the organization that funded, but there are some funds that came for malaria. Then there is a fund from MildMay; they fund HIV testing and counseling.

Interviewer: What about Rheumatic Heart Disease?

Respondent: Not yet, this is my first time. I don't know, maybe it might be there in administration but to me, I haven't heard.

Interviewer: Okay, so tell me about the health care workers and their numbers; do you have enough? Tell me about their qualifications.

Respondent: Okay, the health workers, mostly like half of them have gone back to school but they haven't upgraded them. By the way it's a barrier also; they went back to school many of them but they were not upgraded.

Interviewer: So what you're trying to say is that some of the health workers were at a different level?

Respondent: They are at different levels.

Interviewer: So you are saying that they went back for training.

Respondent: Like the Enrolled Nurses are now registered but at the District, they are Enrolled Nurses, yet they are registered. Even our in-charge here is an enrolled nurse though she is in white (dress code).

Interviewer: Here?

Respondent: Yes.

Interviewer: Wow. So tell me about the waiting times and quality of care they give to the patients; how long do the patients wait to be seen by health workers?

Respondent: Um, that one depends on the condition of the patient; some patients have to go to the laboratory, so it takes long to reach where they get medication. But the health workers are always there, but as you know that patients are many, so they take long, and some tests required take long. So someone can tell you, "since morning, I have been here," or "me I came at 2pm but

you see the time!” That one just needs an explanation like, “you know you had such a problem, you had to wait for the lab and that's why you reached this time.” Otherwise the staffs are always around.

Interviewer: And the quality of care that the health workers give.

Respondent: They are educated, that's why we always have nursing schools that bring their students for more education and that is Nkumba and Mildmay.

Interviewer: Nkumba has a school of nursing?

Respondent: Yes.

Interviewer: Okay, thank you so much. So tell me about the medications, about Benzathine Penicillin; do you have these drugs on sight?

Respondent: We have them.

Interviewer: And anti-coagulants?

Respondent: What are they?

Interviewer: They are like the blood thinners, like Aspirin, warfarin

Respondent; No.

Interviewer: Does the district provide them?

Respondent: Warfarin?

Interviewer: Warfarin and cardiac Aspirin.

Respondent: We have cardiac Aspirin and Benzathine. But we don't have warfarin.

Interviewer: What about the heart failure drugs; do you have them?

Respondent: Heart failure drugs like?

Interviewer: Like Digoxin and Lasix.

Respondent: Lasix, we have, but not digoxin.

Interviewer: That one you don't have. So tell me about diagnostics; what diagnostics do you have here in the hospital?

Interviewer: The what?

Interviewer: Diagnostics, for example Echocardiography.

Respondent: Yes they have. We don't have ECHO, we have ECG

Interviewer: You have ECG! So who does the ECG?

Respondent: There are some people who trained for it.

Interviewer: Okay. So when they do it, who reads the ECG?

Respondent: The doctors.

Interviewer: Anything else? Any other diagnosis which you have here in the hospital?

Respondent: Scan and X-ray.

Interviewer: What kind of scan?

Respondent: These abdominal scans, not CT scan and what.

Interviewer: A normal scan like ultra sound, abdominal scan?

Respondent: Yes, abdominal.

Interviewer: Not like a brain CT!

Respondent: No, we don't have that.

Interviewer: Anything else?

Respondent: X-ray, then laboratory.

Interviewer: So those are the ones you have. So you told me that you do ECGs but don't do Echos?

Respondent: Yes, ECGs.

Interviewer: So tell me about your health information information and medical systems; how are they integrated between the facility's departments; the in-patient and the out patient's? Tell me about your health information systems here?

Respondent: Health information?

Interviewer: Okay, health information like when you receive patients and you see them, do you have registers for these patients.

Respondent: Of course we have registers

Interviewer: What kind of registers do you have?

Respondent: We have a book, a logistics book. Then they introduced the computers now, they are trying so that system can come slowly. A clinician; where she sits, she types,

Interviewer: Where do they register from?

Respondent: At Number one; when the one who registers puts in the computer, those names go to the computers of the doctor, so the doctor just reads what comes on the screen.

Interviewer: So what is Number one? Not every hospital has number one.

Respondent: [Laughs] the waiting area.

Interviewer: Where patients start from!

Respondent: Where the patients start from, then go to triage where they are put in the computer and distributed to the doctors.

Interviewer: So about the medical records system; do you have specific registers for specific conditions, for example registers for Rheumatic fever and Rheumatic Heart Disease patients, or registers for diabetes and hypertension? Do you have different registers?

Respondent: We just have different departments of which they have their registers.

Interviewer: Like?

Respondent: Like surgery, diabetes and hypertension; they have.

Interviewer: But you don't have specific registers for like Acute Rheumatic fever and Rheumatic Heart Disease?

Respondent: We don't have.

Interviewer: So which means that if you're talking about, diabetes, hypertension . . .

Respondent: Those ones they have a specific one and are given specific days when they come to see their doctors for reviews.

Interviewer: Okay. So as a hospital or health worker, do you have any guidelines and protocols for Rheumatic Heart Disease care, including the referral pathways here at the hospital?

Respondent: Maybe the doctors have, but . . .

Interviewer: But if you work with the doctors, at least you would have seen the guidelines and protocols.

Respondent: For Rheumatic Heart Disease! I haven't seen one.

Interviewer: You haven't seen them! Okay, so you are saying that you have not seen any guidelines or protocols for Rheumatic Heart Disease care in this outpatient department?

Respondent: I haven't seen it.

Interviewer: So what about the referral pathways! If you received those kind of patients, how would you handle them?

Respondent: I haven't seen anyone because maybe there are procedures, but I haven't seen anyone.

Interviewer: So which means you cannot know the referral pathways if you have not seen anyone!

Respondent: Yes.

Interviewer: Okay, thank you so much. What makes you leave home and come to work? What are some of the enablers in administration and the leadership that enables you to come and work? What motivates you to come and work?

Respondent: What motivates me!

Interviewer: Yes.

Respondent: They pay me on time, because last month I received money on 22nd, so am on a sure deal that they will pay me. And I think I love to work; I feel free and very comfortable with my patients.

Interviewer: So you said that they pay you very well!

Respondent: I am paid on time.

Interviewer: What about the funding for the healthcare; are you happy about it? Funding in general and in Rheumatic Heart Disease; are you comfortable with it as a health worker?

Respondent: What can I say! I am not all comfortable because today it's my first time to see that there are people funding Rheumatic Heart Disease. So am just eager to see what you're going to give and do for us. I am just happy that there is a program taking on such a disease.

Interviewer: So as a health worker, how are the numbers that you have? For example at this facility, do the number of health workers enable you to provide your work properly?

Respondent: The number of patients?

Interviewer: Yes, the number of health workers. Are you enough?

Respondent: No, we are not enough.

Interviewer: We have been talking about barriers, but now we are talking about enablers to you as health workers; the numbers and qualifications.

Respondent: For qualifications, most of us are enrolled nurses. We would like to go at least for upgrading although there are some issues that cannot help us to go on. But at least people are knowledgeable; however much they have little, they are knowledgeable on what they can do.

Interviewer: Okay, so about the drugs, the medications; do the health workers have enough drugs and facilities to be able to provide care for the patients?

Respondent: It is just once in a time when they are out of stock. In the past it was bad but these days, at least the management has improved; we get medicine, just little medicine. Now those like Digoxin and Warfarin for sure, I haven't seen them, maybe because they don't get such patients or they expire that's why they don't stock them; it might be the reason. What I know is that the administration can explain that very well because there are medicines they bring and they expire.

Interviewer: Okay and then, as a health worker, do these medical report systems enable you to do your work?

Respondent: The what?

Interviewer: The medical records system, like you were telling me about the health information systems or records system. Do they enable you to do your work smoothly?

Respondent: Yeah, they help us.

Interviewer: How?

Respondent: Congestion of patients; that habit of patients standing. Now someone knows that even if I sit, they will call me. The stipulation of duties too, where you know that from here, you go there and from there, you go to such and such place. Those arrangements can smoothen the work very easily, because you know that the patient from here, they have to go to the next step.

Interviewer: Okay, so you have told me earlier that you don't have guidelines and protocols! Because, I was going to ask you how they enable you to provide health care.

Respondent: Me I don't have, we don't have.

Interviewer: And the outpatient department?

Respondent: They just have these . . . they are called NBF.

Interviewer: BNF? Like, British National Formula, but not proper guidelines?

Respondent: Yes, on such a ward.

Interviewer: So question number seven, this is my last question; generally, do you think that patients get the care they need or not?

Respondent: Do I think that patients get what?

Interviewer: The care they need or not?

Respondent: I do think they get.

Interviewer: What about surgery! Do you think they get.

Respondent: They do because we have surgeons.

Interviewer: Because you have surgeons! And in regards to Rheumatic Heart Disease?

Respondent: Rheumatic Heart Disease, I haven't got any.

Interviewer: So according to you, do you think the patients get the care they need?

Respondent: They get the care they need.

Interviewer: Why or how?

Respondent: Because when they come, they find when the health workers are there. If it's about a laboratory, it's there, except for the few they tell, "With this one, you are supposed to buy," or "with this one, you go outside because we don't have it inside." But for the best of the staffs, they do their best so that the patients get the medicine that they are supposed to get free of charge, and that's why you have seen them in large numbers. It is because they know where they are going to get and what they are supposed to get.

Interviewer: Thank you so much. So about patient safety and quality of care concerns, do you think health workers ensure safety of patients, and that the quality of care is given the way it should be?

Respondent: Um, I do because with safety or privacy, each patient goes to the doctor in their separate room, and from there he (patient) has a book that he presents to the pharmacist or nurse; that is privacy. There is no packing for a patient in front of everyone; that is privacy. Then to the quality of care; being that they are handled by qualified staffs, most of the things they do are at least a standard. Another thing is that we are educating; we have students. Everyone tries her or his level best to give the right thing because he is teaching someone, like temperature. You have to explain whatever you do and even the student is behind you to learn what you are doing. So tomorrow, if there are students to treat us, you do the best of your knowledge. We always get CME's at least for some diseases. [Laughs]

Interviewer: So have you had preventable deaths here in the hospital, for example you see a patient, you lose a patient and as a health worker you think it would have been prevented? Have you had any of those?

Respondent: Yes.

Interviewer: What do you think could have caused any of that?

Respondent: Negligence.

Interviewer: Negligence of health workers? Negligence of who?

Respondent: Some of them, it's for the patients; they take long to come to the hospitals. They first go to clinics, and other things I think occur because of money. There are some things that need that, like we can tell you, "buy this such that we continue with our job" and that's when the medical worker is there. Otherwise there are some things that are not in the facility but the patient is supposed to buy them, so you continue with your work and then that time for looking for money comes. The patient will look for money here and there but you find that you are losing someone, and yet also the medical worker also cannot provide.

Interviewer: So do you think that patients are dying in the community?

Respondent: They are there dying.

Interviewer: Without presenting to the hospital for health care?

Respondent: Yes they are there.

Interviewer: Why do you think they could die in the community when there is a hospital like this one which has everything a patient needs?

Respondent: Some of them think of witchcraft! Now let's say I am talking of Rheumatic Heart Disease . . . I have talked but I don't know if I have talked the right thing or not! I don't know because you haven't corrected me whether I was on track.

Interviewer: No, we don't have wrong answers or right answers.

Respondent: But if someone treats flu and cough for so long and he goes to the hospital and gets all the medication for flu and cough, at the end of the day when he gets pain of the heart, he will just end up saying, "now this time this is a witchcraft which has witched me." They are there because we have seen many coming saying that someone or the grandparent bewitched her. At the end of the day, this is a sickness that can be treated, then they die. Now for those that stay on islands, because for us here we get patients from islands, so they say, "we didn't have transport to reach." So someone has died there because of poor transport. So they die like that.

Interviewer: Okay, anything else?

Respondent: Those are the ones I remember.

Interviewer: What in your opinion are the one or two most important things ministry of health could do to improve patient outcomes.

Respondent: To improve?

Interviewer: Yes.

Respondent: For those ones in the islands, it is transport or at least to put a facility there with everything for them. Then motivation of health workers; they need to be motivated apart from the salary they get. I know everyone gets a salary but we need motivation. Then the stock-out; to give enough things to the facility to prevent those stock-outs because some people die because of that money. "You go and buy this" or "we don't have this in the hospital" or "go to CT scan!" In fact there are so many who die because of CT scan.

Interviewer: Anything else?

Respondent: To help people to upgrade; there are so many nurses who want to upgrade, because for me, when I was joining the whatever, the government, they supported nurses or doctors to upgrade because it is a government policy. At least in the hospital, they should take some for upgrading but ever since I got here, I haven't heard anyone going for upgrading because of the government; people just put in their own money to upgrade.

Interviewer: So what about in regards to Rheumatic Heart Disease! What do you think they need?

Respondent: Ministry, to provide for us ECHO, the . . .

Interviewer: Echo cardiography the machine or?

Respondent: The person who can do that, the management, the machine and everything because you never know; I can't say that our doctors are bad or what, they are doing the right thing, but it's because of the patients. If they tell you that you go for Echo, you find that patient goes home and sits because of the money. But if it was the government, you just tell them, "you go for that test and come back to us," (in that case) they would have diagnosed heart disease. I can't say that RHD is not seen here completely, it is. But because of poor diagnosis and investigations, whenever they send them that you go do for me this and this, when they reach there that money is high, so they just sit at home. So they lead doctors into giving poor diagnosis. They provide more to us.

Interviewer: Anything else?

Respondent: The ministry should also give specific training to the worker's about the heart disease and other rheumatic fevers.

Interviewer: Thank you so much for your time.

Respondent: You are welcome.

PARTICIPANT ID	NURSE HW007 - Wakiso
DATE	01/04/2019
VENUE	ENTEBBE WAKISO DISTRICT
AGE	■
INTERVIEWER	

Interviewer: Thank you for giving us this time. This study is to determine how to provide better care for RHD, and that is Rheumatic Heart Disease. There are no right or wrong answers; we just want to hear your opinions. Please be frank and share your opinions. The data we gather is going to be kept confidential and we are not going to put your identity on any of the comments in the reports we produce. Tell me about yourself; how old are you?

Respondent: I am ■

Interviewer: What are your qualifications?

Respondent: I am an ■

Interviewer: Where did you train from?

Respondent: Where I trained from?

Interviewer: Yeah

Respondent: ■

Interviewer: Okay. So how long ago did you qualify?

Respondent: I have worked for ■

Interviewer: Okay, and you have been here since then?

Respondent: Yes, ■.

Interviewer: So doing your practice, what are the common illnesses that you have seen around here?

Respondent: In this unit we have the NCDs and those are non-communicable diseases, Diabetes mellitus, tonsillitis, hypertension, umm and also other diseases associated with those problems.

Interviewer: And when you look at the demographics of the patients, which are the common? By demographics I talk about age, sex. So the common patients you get lie in which age group?

Respondent: Now, we have also like in the DM, we also have young kids but at Wakiso they have a clinic for DM for young ones so we always send them there but here we have from ages up to 70 years.

Interviewer: And then, how about heart disease; is it seen in many patients?

Respondent: At times, because here in our setting like tomorrow in the HT clinic, we always have a doctor here who always assesses them and they give her their complaints and then she prescribes accordingly.

Interviewer: So the clinic is always on Tuesday!

Respondent: Yeah, on Tuesday, the one for hypertension.

Interviewer: Do you participate in that clinic?

Respondent: Yeah, we do participate.

Interviewer: And then, tell me a little bit about your training in Rheumatic Heart Disease; have you ever received any specific training at school?

Respondent: Umm, I do recall. Anyway I think we passed through it but not in details.

Interviewer: Okay, but you have not had any training?

Respondent: No.

Interviewer: How about after training; have you had any training, any workshop where they talk about RHD

Respondent: umm we have gone for workshops but not majorly in this rheumatic whatever, but in other cases

Interviewer: So you have never had any training in RHD?

Respondent: Yes

Interviewer: So since you started practicing, or you have been here for a while, have you encountered any RHD patients?

Respondent: Yeah, I think in the HT clinic we have some like four because at times doctors always send them for whatever . . . I have forgotten the name. They send them for checking their hearts although I have forgotten the term they use, then they come back for results and those ones are already on treatment.

Interviewer: Okay

Respondent: So they always send them there in they bring back the results since they are already on treatment.

Interviewer: So you see them!

Respondent: Yeah, I see them

Interviewer: When do you remember last seeing the last patient? In a week you see like how many?

Respondent: At times we can have none in a week and at times we can get, like tomorrow on a clinic day, there can be like two or three, but not always like on a daily basis.

Interviewer: So in a month you can see how many?

Respondent: In a month they can be either 5 or 6 around there

Interviewer: And then, are they mainly inpatient or outpatient?

Respondent: It depends on somebody's condition; if he is very ill we always admit. If she can go back home, they prescribe for her and she goes and buys the drugs and they keep at home.

Interviewer: Now I am interested in what you have been taught about RHD; what is your understanding of the causes of Rheumatic Heart Disease? What do you think causes that disease?

Respondent: Causes, do I know the causes? [Laughs] I am not sure of them but maybe like someone with mainly high blood pressure and they put her on treatment but she doesn't respond well to the treatment, I think maybe people like that one may have that problem.

Interviewer: Do you know any link between sore throat and RHD? Are those two associated in any way?

Respondent: I think they may be related but I am not very sure whether they are.

Interviewer: You are not sure if they are related!

Respondent: Yes

Interviewer: Okay, so what were you thought that could be done to prevent Rheumatic Heart Disease during school?

Respondent: [laughs] let me see if I remember. But any way I think people should go for checkups to know their status, they check their blood pressure, you have to do exercises and diet also matters. Umm those ones who always have worries, okay that one you can't miss to be there but I think people should not be worried every time because it hikes the blood pressure which may bring problems for them.

Interviewer: What were you told about how to treat a patient with Rheumatic Heart Disease?

Respondent: This being a big hospital, we always get patients that have been already seen, like we have a physician here and if the case is for him they are always sent there and a doctor prescribes for them. Then for us we just give the treatment.

Interviewer: What treatment do you usually give these patients who have Rheumatic Heart Disease?

Respondent: Umm, it depends; we just give according to the prescription but I think most of their drugs, like maybe Trovas and what. Some of them we don't have them at the hospital. They are sent to go and buy them. But if they are prescribed what we have, we always give them.

Interviewer: Okay, is there any that you have that you know treats this disease?

Respondent: No because it is always a combination of the hypertension drugs and the other. So for us we just give what we have and we tell them to go and buy what we don't have.

Interviewer: Do you stock Benzathine?

Respondent: Benzathine injection? Yeah; in our outpatient we have but here we don't

Interviewer: What about Warfarin?

Respondent: That one I don't know whether we have it because for us we always order what we supply to our patients. So some of the drugs are being supplied through the pharmacy at the OPD

Interviewer: So you don't have those drugs!

Respondent: No

Interviewer: Then, are there any aspects of Rheumatic Heart Disease management which you think you need more training in?

Respondent: Yeah; if there is a chance of being trained, we want to be trained

Interviewer: Which areas would you want to be trained in managing Rheumatic Heart Disease?

Respondent: Umm, management throughout the management, the drugs, the dose and how to talk to these patients to give them advice accordingly.

Interviewer: So what is your understanding about the long-term prognosis of Rheumatic Heart Disease?

Respondent: What I understand is that if someone has that problem for so long, either she is not getting the drugs properly or taking them properly and the thing just continues to be there.

Interviewer: Okay, tell me about your encounters with these patients who have Rheumatic Heart Disease. Do you remember the last one you saw?

Respondent: Umm, usually when they are given the prescription to go and buy the drugs, they always complain that they have no money. Others may say, "I am a lone; I have no one of my kids because they all died." They always have complaints.

Interviewer: Okay. And umm, the last one you saw, was it a female or a male? How old was the last patient you saw?

Respondent: Umm, the last one was a lady

Interviewer: How old was she?

Respondent: She was between 60 and 70

Interviewer: What did she complain of? What symptoms did she describe when she came here?

Respondent: So some have different matters: others are weak and they complain of having sleepless nights at times, no appetite, and palpitations

Interviewer: when you look at these patients do you think they know of an association between RHD and sore throat?

Respondent: I don't think.

Interviewer: They don't know!

Respondent: Yeah

Interviewer: And then, when you give them the drugs and treatment do you think they adhere to the treatment? Do they come back for follow up?

Respondent: Yeah, they always come back because we always give them a return date.

Interviewer: And what motivates them to come back?

Respondent: They care about their life:they do care. When you tell them to come back on such a day they always come back.

Interviewer: Do you have some who miss?

Respondent: Not usually. Maybe someone can miss if she is weak and don't have any one to bring her. That's when one misses.

Interviewer: And the distance they travel; where do they come from normally?

Respondent: Within Entebbe, others may come like from Kajjansi, Ndejje around there. Even some can come from Kampala, because we have cases which changed from Mulago and started to come here.

Interviewer: Although they stay in Kampala?

Respondent: Yes.

Interviewer: Why do you think?

Respondent: Maybe they are comfortable coming here because at times they were saying the numbers in Mulago are overwhelming so they decided to come to Entebbe or they don't stay long like in Mulago.

Interviewer: Now, you know for Rheumatic Heart Disease, patients have to come monthly to get their treatment. So for those who don't come why do you think they miss coming for their doses? Why do you think some people stay in the community?

Respondent: Some may get tired, others may have someone to buy the same drugs if they have the prescription. They may tell someone, "you go to the drug shop and buy those drugs" and they continue taking.

Interviewer: Any other reason why some people choose not to come?

Respondent: Others its poverty; transport can fail them, others maybe be very weak and they can't come alone and there's no one to help bring them.

Interviewer: Okay, for those few who you said do not come on time, which other reasons do they say for missing doses?

Respondent: Some are just reluctant; someone may have no reason and they say "doctor I didn't come, I couldn't." So like that, when there's no major problem. At times when they feel okay they just relax but there are others who are very active, when you tell them to come on such a day, they do.

Interviewer: Why do some people come when they are very sick?

Respondent: That one at times when the drugs are finished they stay without taking them so someone can spend like a month without taking the drug and when they feel very sick, they are like "let me go back to the hospital, I am going to die from here."

Interviewer: Okay and then, what sort of barriers do you face when providing services to these patients like those who come with Rheumatic Heart Disease or even other conditions?

Respondent: Others are too poor; they may come when we have stock outs so you tell them we have prescribed a list of drugs then they say, “doctor!! I won’t be able to buy it because I do not have any money. Even the transport to get here someone just helped me with it!”. Such things; poverty, no transport, no care takers. It being a chronic disease, others are just neglected by those who can buy them drugs. They say “hold on there’s no money, I will buy when I get money.”

Interviewer: Okay, and then let’s look at the local health system barriers on the side of the providers. I am going to be mentioning some of the things and tell me if they are working for you or not and tell me why. Let’s look at the administration here; is working for you? Is it helping you do your work well?

Respondent: It would have but at times the stocks in this hospital is always not enough because they may think the drugs they are supplying will take us for three months but within one month the drugs are out of stock.

Interviewer: What is hindering those people who ask for the drugs to have do better projection so that they ask for enough drugs?

Respondent: They always limit them, like they can say we want this and this but they go on cutting the budget, and the money they are supposed to use to order for things is not enough.

Interviewer: Okay, and then what else is not working for you with the administration or what is working for you in administration?

Respondent: Umm, any way it’s always the stock outs but we used to have some people, like MRC guys who used to give us some drugs which was doing good for us because at that time apart from insulin from the DM patients, we used to have the tablets for hypertension, the DM drugs were always in plenty but these days they withdrew. They had come in for five years and now that they are over, like now the insulin is out of stock and we don’t have any, so the people coming on Wednesday will cry from here. First of all insulin is very expensive, some can afford and some can’t afford to buy. Even the tablets, like now they brought only 30,000. So already we are... it’s not even a month but the drugs are already finished. So such problems are there, mainly stock outs.

Interviewer: How about leadership in the district; is it working for you?

Respondent: Huh, that one [Laughs] . . . I don’t know but for us if things are there, we always order and we give our patients and they become happy.

Interviewer: How about the funding for health care in general?

Respondent: But the funding I think they are limited so much, they don’t give them enough. They should add on because the patients are increasing every day. Like here in our clinic, we always get new cases every Wednesday, those of DM on Wednesday and those of blood pressure every Tuesday.

Interviewer: How about funding for Rheumatic Heart Disease in particular. How do you see it here in the hospital?

Respondent: That one I really don't know maybe you can get a better from pharmacist who always orders for drugs. I think he knows the better answer for that.

Interviewer: Okay, if you look at the health care worker numbers and qualifications, how are they? Let's start with numbers; are they working for you? The staff numbers!

Respondent: The staff numbers, when we are so busy we get some assistance from other staffs but the hospital is going to be lifted to a referral status, so we are expecting to be given more nurses and other professionals.

Interviewer: How about the qualifications of health workers here, is it working for you?

Respondent: The qualifications, I think it's good because most people have gone back to school so they have added on books.

Interviewer: Waiting time for patients; how is it?

Respondent: We are trying to limit it because like here now when we have very many patients, we try to give them numbers so they don't complain "I came first, or you are passing me." So we give them numbers and we are in different whatever, so someone may be taking the blood pressure, others weighing, recording the NCD books, clinical officers prescribing, others dispense and record in the books. The way we follow the orders, they don't over stay.

Interviewer: How about the quality of care you give them; how do you look at it?

Respondent: We always give them health talks and we always tell them to ask questions where they don't understand.

Interviewer: And the medicine you have talked about, tell me about the heart failure drugs. Do you have them in stock here?

Respondent: At times we have, there are some promoters who always come and supply us some. They have done a lot because they give us some and we give to them (patients). At times we give a full dose and at times we give some and tell them "if these ones get done make sure you buy and finish the dose"

Interviewer: How about the anti-coagulation drugs; do you have them here?

Respondent: I think they are there.

Interviewer: You have!

Respondent: They might be there in the pharmacy or the stores because other drugs we can't know because we don't know much.

Interviewer: How about BPG, do you have it?

Respondent: What is that?

Interviewer: How about diagnostics like echo-cardiography?

Respondent: That one I am not very sure.

Interviewer: How about the heart patients here, do they get examined?

Respondent: The doctors examine and then at times they refer them to physicians to be checked. At times they are given whatever to go and check.

Interviewer: Okay, and then when you look at the health information system or the medical record system you have here, is it working for you? The way you keep records, the way information flows from in-patient to out-patient, or in case you need information from another department is it easy to access that information and does it flow . . .

Respondent: I think that one is easy although now we are starting a system of using computers in every unit, so we are starting that system here. We are not yet used to it and the computers are not enough but every unit is being given a computer. I think it will be good.

Interviewer: Okay, and then do you have registers for different diseases like for Acute Rheumatic fever, and Rheumatic Heart Disease?

Respondent: We have one for NCD and the general one.

Interviewer: And do you have guidelines and protocols for Rheumatic Heart Disease care here?

Respondent: Umm these promoters used to give us some but as we are having 5As, those that are not laminated are not supposed to put on the wall to stick, but we have some.

Interviewer: For which diseases?

Respondent: Like that one for DM.

Interviewer: How about for Rheumatic Heart Disease; do you have any?

Respondent: There was a time they gave us some but we had nowhere to hang them.

Interviewer: Who gave you those ones?

Respondent: Those promoters they come and distribute their drugs.

Interviewer: But have you seen any guidelines on how to manage Rheumatic Heart Disease?

Respondent: I think others but not our unit. I think in the ward, those people who admit patients might have some but for us here we don't have because for us we don't admit; we just work on them and they go.

Interviewer: I understand, so for these things I have mentioned what has worked for you? Administration, funding, health care workers, drugs, information flow and guidelines, what is working for you here?

Respondent: But I think a combination of all; it is good if it is in the system.

Interviewer: But currently is it working for you?

Respondent: There are some loopholes somewhere. It is not 100%, but they are try.

Interviewer: So where do you want them to put more effort?

Respondent: I think the stock outs; if the drugs are there and the patient comes and you give him everything, it will be good.

Interviewer: So what makes you to keep working despite those short comings?

Respondent: It is positive attitude, and then the umm, and good working relationship and team work.

Interviewer: Now let's look at your perception of patient outcomes; generally do you think patients get the care they need here?

Respondent: Yeah, they always appreciate and at times they bring us some things and be like, "doctors, thanks for treating us. You are so caring." They appreciate.

Interviewer: Okay, do you have any patient safety or quality of care concerns here?

Respondent: Umm . . . no

Interviewer: You don't have any!

Respondent: We don't have any except that they are too forgetful; at times they forget their things here and we give them back but stealing here in our place, no.

Interviewer: How about when you are providing them with services, do you feel like people do whatever it takes to make sure they are given services in a hygienic and safest way?

Respondent: Yeah, for us here I am sure the cleanliness is okay. We don't have any issues.

Interviewer: Okay, so if you look at the quality of care for your patients here, how is it?

Respondent: The quality, it is good.

Interviewer: Why?

Respondent: Because first of all we are clean and we always work in a clean environment, we do the needful. We have drug envelops where we always pack for them; we have no problem.

Interviewer: Have you seen any preventable deaths here occurring here? A death which wouldn't have occurred but it occurred.

Respondent: No, maybe on the wards when they are admitted but here we have never had such.

Interviewer: Do you think patients are dying in the community without presenting to the hospital?

Respondent: Yeah, there are there who are dying.

Interviewer: Why?

Respondent: Some of them have that thinking that they are being bewitched and they just use local herbs assuming they have been bewitched, so they can die from there. Others are too poor; transport is a problem or someone to escorts them is at times the problem.

Interviewer: And then in your opinion what are the two main things Ministry of health can do to improve outcomes in our hospitals?

Respondent: I think they should do outreaches deep in the villages and just talk to those people as they come to know such diseases, the signs and symptoms and what they should do. Umm . . . I think that can work.

Interviewer: Okay, anything else before we stop?

Respondent: No.

Interviewer: Okay, thank you so much for your contribution and input to this study, we shall use the information to make there's improvement in RHD services.

PARTICIPANT ID	PHARMACIST – HW008 - Waskiso
DATE	
VENUE	ENTEBBE WAKISO DISTRICT
AGE	■
INTERVIEWER	

Interviewer: Okay, thank you for accepting to have this interview with me. Now umm, just to remind you, be frank with your opinions and share your opinions. We are going to keep your information confidential. There is no right or wrong answer. Whatever you say is what we take and we want to provide better health care for RHD patients. We shall not leak your identity to your comments in any reports that we produce. So tell me a about yourself, how old are you?

Respondent: I am ■.

Interviewer: You can leave out the name. How old are you?

Respondent: I am ■.

Interviewer: Tell me about your qualifications; what are your qualifications?

Respondent: I am a ■.

Interviewer: OK, and then, where did you train from?

Respondent: I trained at ■.

Interviewer: And when was that?

Respondent: I finished in ■.

Interviewer: And how long have you worked here at Entebbe?

Respondent: These are ■.

Interviewer: So when you look at the patients that you have been seeing, if you can tell me about their demographics; their age, which is the dominant age you are seeing among your patients?

Respondent: Umm, most of them I would say are adults because, first of all we have many adult health units and the pediatric section being anemia. The others are treated in their own wards.

Interviewer: Males or females? Which one is the common?

Respondent: The largest number are females.

Interviewer: And which are the common illnesses which are being treated?

Respondent: Commonest illnesses; we have STDs, we have mostly STDs and Respiratory Tract Infections then ulcers.

Interviewer: Okay, then let's talk about your training in Rheumatic Heart Disease; have you received any specific training during school about handling Rheumatic Heart Disease?

Respondent: Rheumatic Heart Disease, we read about it but there wasn't much details I would say.

Interviewer: But you had some training in school?

Respondent: It wasn't training as such, it was more of lectures.

Interviewer: Okay, and after graduation have you received any training in handling Rheumatic Heart disease?

Respondent: No.

Interviewer: No! Okay, and in your practice; how many patients with rheumatic disease have you seen?

Respondent: They would be around four.

Interviewer: Like four! The four you have seen them here?

Respondent: Here I have not seen

Interviewer: Not even one?

Respondent: Not even one

Interviewer: Okay.

Respondent: I don't know whether the diagnosis are not . . .

Interviewer: You have not seen any patients of Rheumatic Heart Disease?

Respondent: Maybe there could be another reason for that because we have what we call diabetic and hypertensive clinic, and it is up there. So it could be that most of the Rheumatic Heart Disease patients are handled from there; they do not reach this side.

Interviewer: Do they have a separate pharmacy there?

Respondent: No. They have a unit; they have some drugs but what they might not be having they come this side.

Interviewer: So this is the central one!

Respondent: Yes.

Interviewer: OK, then it's you handling most of the patients

Respondent: But now those ones, like there are some units like psychiatric, HIV, Tb and then hypertension. They usually have their basic drugs.

Interviewer: They only come here when they don't have the drugs!

Respondent: Yeah

Interviewer: I understand. Okay, now, what is your understanding of the causes of Rheumatic Heart Disease? What do you think causes it? Okay, from the little that you had from school.

Respondent: Rheumatic Heart Disease usually is what we call Rheumatic fever. So most of them come as infections and if they are untreated, they keep on progressing affecting the valves of the heart, the joints.

Interviewer: OK, now, are you aware of any links between sore throat and RHD?

Respondent: Any link?

Interviewer: Is there a link? Are they associated; sore throat and Rheumatic Heart Disease? Are the two associated?

Respondent: I would say they could be. Okay, sore throat can be categorized, it's that they are all allergic or bacterial or fungal; it can be either of them. Most of them could be strepto, so they come as strepto and then they have a link to Rheumatic Heart Disease.

Interviewer: So what where you told can be done to prevent RHD?

Respondent: Preventing RHD . . . [thinks] that's some good time back. Umm, but mostly, I think as a basic of managing that infections, it goes hand in hand with sufficient hydration especially warm fluids. That would play a big part, and also the intake, what you have taken; the infection of contaminated food. Some people are so much interested in taking clay and soil, so that could be one of the factors that could escalate the condition. So the risk factors; the intake and then the management or prevention.

Interviewer: What where you told can be done to treat it?

Respondent: umm, there must be some operation on this especially the ones with streptococcal.

Interviewer: Are there any other aspects in RHD management in which you think you will need more training if they were to offer you training in RHD management? Which areas would you want to be taught, or to be trained in?

Respondent: I think mostly, because now, currently due to my exposure I have not got those much cases of Rheumatic Heart Disease. And you know training keeps on, I mean Mildmay keeps on revolving, so since am not exposed, maybe I need some training about Rheumatic Heart Disease treatment.

Interviewer: Apart from treatment, any other area?

Respondent: Of course if I go for treatment, then it will encompass all aspects; the complications and all that.

Interviewer: What is your understanding about the long term prognosis of RHD?

Respondent: The long term prognosis, those would be like the complications. Umm, I think it can lead to a heart failure because if the valves can't contract, the blood will be mix up with in the heart and then it collapses. It will also lead to an infarction which eventually leads to heart failure. Basically, infarctions and heart failures. Umm, it can also lead to septicemia or that general blood infection. Because if now the heart that supplies blood to the general organs is affected then . . .

Interviewer: Okay, so you said that you have encountered four in your experience!

Respondent: Yes, sometime back [laughs]

Interviewer: How long ago?

Respondent: How long?

Interviewer: How long did you last see a patient with RHD?

Respondent: I think it was around early 2017

Interviewer: 2017! Where was that?

Respondent: I was still during practice in pharmacy

Interviewer: Umm the last patient you saw, do you recall that day? Tell me about it; how was that patient present?

Respondent: umm, that one, umm . . . but I think she had some, because she was a lady and she had some general body weakness. She had some profuse sweating. I don't remember others because she didn't come alone; she had some caretakers.

Interviewer: Okay, how old was she?

Respondent: She was around 54

Interviewer: How about the other three; in what age did they fall?

Respondent: Most of them they were about 60.

Interviewer: Did they look like working people, or they don't work?

Respondent: Some of them, according to how they were dressed they looked to be either working class or self-employed.

Interviewer: So the four, were some adults and children or they were adults only?

Respondent: They were adults

Interviewer: And do you think these patients know the link between sore throat, acute rheumatic fever and rheumatic disease?

Respondent: Most of them knew with time. Actually some of them had known because they have been treated with that same condition for some time, but then there are others who had no idea how it all started. Because someone would tell you that I have pressure or what but now I have this, and then basing on the diagnosis and the likes, you have to inform the patient how it comes about. You may find that some of them already have the risk factors that could lead to that; someone's history, like what they used to take, dehydration itself. Then also the environment.

Interviewer: So when they come, what sort of symptoms do they present themselves? What do they see?

Respondent: Some of them could tell you some little chest pain, though it's not much. Then someone can come with joint pains, some temperature increase.

Interviewer: So, those patients that you saw, tell me about their follow up and adherence to the drug.

Respondent: Most of them I didn't take that much concern because we used to keep on rotating; you couldn't be on one branch for more than a month.

Interviewer: What do you think are the barriers? What is stopping them to come for care or why do they come late?

Respondent: You mean those who already have or . . . ?

Interviewer: Those who already have RHD

Respondent: What I think, we have two issues now; because, some people can get that condition but since it starts as maybe a strep, most of them self-medicate. If someone comes maybe you give some treatment according to what they . . . because some of them keep away some history, so you might rely on the provided history to try to manage what they have told you. So you are managing a respiratory tract and since most of them are sore throats, don't give out antibiotics. So you recommend them warm water, ginger, eucalyptus leaves and the likes. So the progress might be controlled unknowingly and by the time they know that it is now serious is when they are already down, or when maybe somebody comes to you with a chest pain and when you try to check the history, that person has nothing like carrying some heavy things, no accidents and no trauma. So that's when you recommend them to go get a chest X-ray and by the time they go for a chest X-ray, the disease has already progressed to some extent.

Interviewer: So it's self-medication and ignorance!

Respondent: Yes, it is self-medication and ignorance about the causes.

Interviewer: How about those ones you give appointments to come back maybe after two weeks, to come back every month, what do you think stops them from coming?

Respondent: I think most of them I would say, most of them would be occupied because now, take an instance; you can give someone maybe a 10 day dose and you tell him to come back after two weeks or after 10 days. When those days elapse, someone doesn't come in. The only time they come back is when they have another condition or maybe when the condition has relapsed, and when you ask him why didn't you come back, he tells you 'my work' or 'what I am doing I am the only person there so I couldn't leave someone when I am okay.' So some times the relief somehow prevents them from making reviews. Others, others are taken up by other people's information; sometimes you handle a person and you tell them what they are meant to do, but because they had a person who had some similar condition, or maybe for them they perceive it as a similar condition but clinically it is different. So because of the peer influence they don't turn up.

Interviewer: Any other reason why you think some people don't come?

Respondent: Another reason, personally I think is the improvement they get because if someone came with chest tightness or maybe difficulty in breathing but he is relieved, some of them don't come back. And then there are others who also have poor health seeking habits; they only come back when they are badly off.

Interviewer: Okay, thank you so much. How about you people who are providing care! Now you said you have not seen even one patient.

Respondent: Here I have not.

Interviewer: Why do you think it is like that? There is no RHD in Entebbe?

Respondent: Okay, mostly we have more of interns during day time and so somehow I think it affects the prevalence. I would say prevalence because if something is not noted then you wouldn't know. But the actual thing is that the conditions would be prevalent but I would think it would affect the documentation or maybe for the conditions because, for them they might go with what they commonly see with their seniors; 'if it is something like this . . . if it is something like this . . .' and if something is not prevalent at the facility, then there is no concern put against it. Personally I think that would be the cause because mostly the people we see here would be heart failure, kidney failure and what, but Rheumatic Heart Disease . . .

Interviewer: So if someone came with heart failure, does the hospital manage them here?

Respondent: We have been getting those people. I think they have been well managed.

Interviewer: But RHD you do not?

Respondent: With RHD I think what affects is what I have told you; some people don't have much experience and when you are at the window and you see the flow, fine you can see the symptoms and then you can try to relate.

Interviewer: Let's look at the local health system barriers and you are going to tell me which systems are working for you here and why do you think they are working for you. If you look at the administration right from the district, is it working for you? Is it helping you to do your work better here?

Respondent: The administration from the district?

Interviewer: Yes, before we come to the local administration

Respondent: Umm, I have not experienced that much influence from the district because most of the things we have been running them generally as the hospital. I have never really . . . okay, it's only like once or twice and usually the support we get so much is for HIV and I think that's when we get some people from the district to come. Otherwise in other conditions, not so much. Mostly we have CME's on Tuesdays and that's within the hospital.

Interviewer: How is the attendance?

Respondent: Attendance, I would say it is fairly good. The only concern would be . . . okay for the intern doctors and most doctors, because mostly they are supervised when they are going to discuss and all of us would be equipped with a copy a week earlier. Of course each one of us has a duty to research about something such that when they talk something, you know what they are talking about; you can supplement and can correct. So we do CMEs every Tuesday.

Interviewer: Have you had any RHD topics coming back

Respondent: No.

Interviewer: It has not happened.

Respondent: Basically the circulatory system hasn't been much touched on though they say that clinicians have not been that bad especially those of OPD; they try, but this side is lacking.

Interviewer: Why? What is unique about the outpatient department?

Respondent: Personally I don't know why. Maybe could it be the system favoring them, because if you don't have any one to report to, um! You know government things, hmm.

Interviewer: So how is the administration? Is it helping you do your work here?

Respondent: I think the administration is trying its best because like I told you, we have CME's on Tuesdays and we have departmental meetings on Friday, but I think somehow we are limited and I heard that it operates within the budget. So I think their efforts can be somehow sabotaged at one point, because if you take a look, we have something which maybe has just come up but some projects work on funders and donations. I think somewhere some effort is not being put in because of the limited resources but otherwise for what they can do, I think they really try.

Interviewer: So let's talk about your departments where you deal with the drugs, how is it? Is it active?

Respondent: yeah

Interviewer: Do you have all the drugs?

Respondent: Yeah, and like I told you, we have the basics but we are limited because some conditions . . . okay the antibiotics we have, we are also limited I would say and that also brings about the poor prescription habits; someone prescribes the same thing . . . the same thing because it is what is available. Buy now, because antibiotics have symptoms because someone can say, "uh, Ampicillin can work for this" so he gives Ampicillin and yet the condition or progress requires something better than that,

Interviewer: Okay. Do you have benzathine?

Respondent: We have

Interviewer: usually it is prescribed to which kind of patients?

Respondent: Syphilis. Mostly, I think that is the only condition.

Interviewer: Do you have heart failure drugs here?

Respondent: heart failure we have, though we don't have things like (min) which I think could be the first line, but the others we have.

Interviewer: Anti-coagulation drugs, do you have?

Respondent: Coagulants we have Aspirin. It is basically Aspirin.

Interviewer: Do you have Warfarin?

Respondent: Warfarin is sometimes up but there are other blood pressure . . .

Interviewer: Did you say there is a dispenser there we can talk to?

Respondent: But those ones are not dispensers; they are just nurses. They are just experienced [laughs].

Interviewer: Eh, so they are the ones they use to dispense?

Respondent: Yeah

Interviewer: Then I will talk to one of them. And then do you have BPG, do you have diagnostics like echocardiography? Do you have it here?

Respondent: No

Interviewer: And then, let's look at the health workers' numbers; is that working for you? How are the numbers of staff?

Respondent: I would say we are under staffed

Interviewer: Understaffed!

Respondent: Totally understaffed because now the physicians are few and being few, they stop working at 3pm. So now in the evening, sometimes you can have high patient load with no doctors because for us, much as there is someone, we can also the work but we cannot do prescription. So you find that a large number of patients would be served by one person. How would I do that? Someone just writes whatever comes their way and that's why I told you that that could be the cause for those patients with heart conditions; the interns, the nature of staffs

Interviewer: When you look at the waiting time, how is it for patients?

Respondent: Of course being that staffs are very few [laughs], but it can be okay sometimes. There could be some good number of people there and it also depends on the retention of those interns. If there is a good number, like around three for adults, two for pediatrics then the flow would be good

Interviewer: Like someone would spend how much time in a day?

Respondent: Sometimes we are interrupted by emergencies but otherwise on a good day, when all the people are there, at the pharmacy people take like 5 minutes because most of them we have to refer but then there are those that we don't refer. So those ones would take us around that time.

Interviewer: Okay. So in your opinion how is the quality of care you give to your patients?

Respondent: In the pharmacy we do our best because when you try to do the prescription, you don't just prescribe; you try to see any errors, you go back to the doctor such that they correct them. So I think at our side we are doing our best because we also do CMEs we try to provide those issues but then I think what will affect us, we should probably get some staffs in some departments.

Interviewer: Which departments are really understaffed?

Respondent: It is mainly the OPD and I think that gives the general view of the hospital; if OPD is poorly staffed then . . . then with the quality, I think we also need of also need some good drugs.

Interviewer: When you talk about drugs, where would you want to have more stocks?

Respondent: I think we need more cardiovascular drugs although I know, huh, I think they are affected by cost because they are generally expensive, but we need more at least things like Albuterol and those emergency drugs. Because I think for emergency drugs, at the moment we have Frusoline

Interviewer: Okay, when you look at the health information flow, how do you keep it? Is it working for you?

Respondent: We are trying to reinstall a system but by the time they brought it, it wasn't developed. They are trying to develop it on ground. So some how it affects our work; sometimes they tell you to use it but then the prescribers are not using, but otherwise if they install the system it will be fine. Then the phone networks are also not good, otherwise if they were fine you could just make a call to them.

Interviewer: So how about the flow between the in-patients and out-patients; is there a coordination?

Respondent: Yeah, like I told you we have the outpatient and inpatient sections, we assign numbers to those people; if it is an OPD number, then it is an outpatient. For inpatients, we to give some medicines, basic medicines because we are not here for so long. So we give them some medicines just in case we are not around, and they also bring their files during day. Caretakers or the nurses can bring their files and then we serve them. Then we have records where we follow up inpatients and outpatients.

Interviewer: Is it easy to trace a record of someone who came a year ago?

Respondent: Yes

Interviewer: So does that mean it's working for that you are okay with the information flow and records system?

Respondent: I think we have been using the manual system, so far it has been manual but I think that if we restore the computer system it will be far better in terms of time.

Interviewer: So do you have different registers for the different conditions here, like if I wanted to look at the . . . of course you said that you have not seen the RHD patients but maybe for TB patients?

Respondent: Yeah, TB patients are there most of them are at the same clinic with HIV because we make weekly reports. Those weekly reports contain number of patients received, the most prevalent condition, the medicines we are meant to get and what is not available for distribution. So I think the records are well kept at any point that you want; at the pharmacies, TNO . . . I think they are there.

Interviewer: Eh, good to hear that. Do you have guidelines or protocols you use for . . . now you said you don't handle RHD here!

Respondent: Yeah

Interviewer: but could you be knowing the referral path? What would you do in case got a patient with RHD?

Respondent: RHD?

Respondent: Because they know this is a hospital.

Respondent: Usually patients who come for emergencies, they are taken to emergency room, so they are given some basic care just to improve the condition and given some rest and they are referred to big wards.

Interviewer: So have you seen any RHD protocols here?

Respondent: Not yet.

Interviewer: So looking at all these things you have gone through, how about the funding! When you look at the funding for health care, is it working for you?

Respondent: Funding is very, I would say poor. It needs to be doubled or tripled because most drugs and equipment, we have a two months' gestation period waiting for the supplies but sometimes the supplies might be small and they can take you for a month and a half and of course you try to give the patients half doses and tell them to go and refill in the pharmacies, but some drugs are not there. So you realize you are speaking what is not applicable [laughs]

Interviewer: You don't have! Because, you are near NMS . . .

Respondent: Yeah, we are near NMS but we are not exceptional from any other facility. As long as you are not given the money you cannot . . .

Interviewer: So from what you have said, at least the administration is working for you, and then the health information, funding no, health care no, the numbers are low, is that right?

Respondent: The numbers are high

Interviewer: I meant for healthcare workers

Respondent: For healthcare workers we need some more especially, more and qualified.

Interviewer: Actually let's talk about qualifications; when you look at qualification of the workers, what is your take on that?

Respondent: Qualification is not bad but the only problem I would say, okay since some of them are old they are so much reluctant; they know how the system works and they know the loopholes in the system. So, and also the information that is being put back is very different from what is going on. So you see, and they are the same people who are not attending CMEs. So that is how they affect us. So you find that you are at the window but you have to keep on going to each of them that has prescribed to carry out the prescribed. So I wouldn't say that they should be taken away but I would say that we need some more who have the urge to improve. Yeah.

Interviewer: So as you do your work, what has motivated you to keep doing this despite all the challenges around?

Respondent: I think I like my profession and I like creating a difference. I don't think we are still at the same level I found.

Interviewer: And then, let's look at your perception at the patient outcome. Generally do you think the patients get the care they need here?

Respondent: I would say they do. For patients, they can't appreciate if you don't have the drugs. But for me what I think is that if you have talked to the doctor, they have sent you to laboratory, they have sent you to the cardiograph department and they have known what you are suffering from, I think that would be enough for a person. So I think the patient care is not bad; we are really doing our best.

Interviewer: How about those who need surgery, do they get the care?

Respondent: Yeah

Interviewer: They do!

Respondent: Very well, and without sepsis [laughs]

Interviewer: Do you have any patient safety and quality concerns apart from your concerns you as you?

Respondent: Like?

Interviewer: Patient safety like how you handle them, the environment, the equipment you use. Basically do you think everything is done to make sure that the patients are treated in the safe way and that the quality of care given to them is okay

Respondent: Sometimes they will be affected by equipment like gloves; gloves can be completely done and the nature of patients we receive, most of them are from the islands, most of them don't have money, most of them have issues. So it would affect because, if the patient comes and you don't have gloves, it's not me who is supposed to buy gloves; they are the patients. So most of them in their understanding would think that maybe doctors are doing it to get money from them, but I think the equipment are lacking in every department because even when you go to the laboratory, sometimes they have issues. Everywhere there are issues but I don't think . . .

Interviewer: Like in the laboratory what issues do they have?

Respondent: Sometimes the system will be down and that could affect them because there are some tests that can run for two hours, those genetics sometimes. So basing on the patient's condition, some people can wait long but I don't think . . .

Interviewer: In general do you think the symptoms of the patients are really taken care of?

Respondent: They are. I feel they are taken care of because if a person comes in and we see that the condition is not good or is likely to affect others, we usually separate those people, or if you see someone geriatrics or someone is too old and they can't wait, we usually forward them first. So for accident people and what, we usually handle them before others.

Interviewer: And then, do you think there are some preventable deaths that are occurring here?

Respondent: Preventable deaths?

Interviewer: Yes, maybe there is a death that you look at and you be like, *"this one shouldn't have occurred!"*

Respondent: I think sometimes I think, like I have told you some equipment are not enough, like oxygen cylinders. So they are trying to put some oxygen whatever . . . what is it called? The one which they put . . .

Interviewer: In the wards!

Respondent: Yeah, but somewhere they said in June or some time before. So sometimes it can affect some people who are brought and they are in bad condition. I think there is a case that was lost some time but it was because of oxygen; cylinders are not enough and those few that are there were not repaired. Then there are those, because you don't have the basics, like I told you especially in cardiovascular system, sometimes most of them are brought in bad conditions and there those who come

and there is nothing like they are better off or nothing like drugs or IV. So you might lose those people in a hypertensive crisis.

Interviewer: Then do you think there are some patients who are dying in communities without presenting to hospitals?

Respondent: I think most of them are there due to poor health seeking behaviors. Most of them are there because now there are people who come and tell you, or someone dies at the gate or someone dies as soon as they have entered the ward.

Interviewer: But why?

Respondent: Because for most of them, as soon as they discover they have a condition it's when it's almost the last stage. So many of them die because those who die from out, they don't come here. So I still think they do.

Interviewer: So what in your opinion are the two most important things Ministry of Health should do to improve patient outcome?

Respondent: umm I would think they can do some monitoring not only at human resource level, but in all aspects. I think they shouldn't take that longer time to keep checking on what is happening because there are some things we discuss that have been identified and they are still happening. I would say of there would be more like, I don't know whether it's the MS' work to report but I think they also need to put in some efforts to keep checking, and also because if they keep checking, then also there will be more sensitivity about some conditions, sensitization. If you ask for the papers or 'where did you write this' then people can be more vigilant about documentation. And also, I have rarely heard of those Ministry of Health CMEs; most of them that am hearing or that I have attended are just for some few bodies like PSU, Intra Health, Reproductive Health and the like, but not from the ministry. I think they need to do more, and also reassessing the staffs especially those who have been in service for long; are they still capable to serve?

Interviewer: So what can they do for RHD? What should Ministry of Health do for Rheumatic Heart Disease?

Respondent: I think we need like a seminar. A seminar, conference, leaflets, and those books. I think they need to do that or even . . . umm, yeah basically the seminars and literature.

Interviewer: Any other thing before we finish?

Respondent: Any other?

Interviewer: Anything you want to add on before we finish.

Respondent: umm, no

Interviewer: Okay, thank you so much for your time, we appreciate and we shall use the information to help and make the RHD program, management and prevention better. [switches off recorder]

PARTICIPANT ID	HW009 - Wakiso
DATE	26/03/2019
VENUE	BUWAMBO HEALTH CENTRE WAKISO DISTRICT
AGE	█
INTERVIEWER	

Interviewer: We are happy to have you here. What language could we use?

Respondent: Let's use English

Interviewer: So we are going to ask you a few questions. In this study we want to know how we can provide better care for RHD. There are no right or wrong answers and we ask you to be frank and share your opinion. The data we gather is confidential and will not link your identity to any of the comments in any report that we produce. So first tell me about yourself; how old are you?

Respondent: I am █ years old.

Interviewer: And what are your qualifications?

Respondent: █
█

Interviewer: Nice to meet you. So where did you train from?

Respondent: You mean for my █ . . .

Interviewer: █

Respondent: I trained from █.

Interviewer: █ ..

Respondent: █ ..

Interviewer: █

Respondent: It was introduced there in █.

Interviewer: How long have you been working here at Buwambo?

Respondent: This is the █ year

Interviewer: Where were you before you came here?

Respondent: █
█
█
█

Interviewer: So when you look at the demographics of the patients for those years that you have practiced, how are they distributed; the age groups? Whom have you been seeing mainly in terms of age group or sex among the patients? Have you been seeing more women or more men?

Respondent: It is more women because I am mainly on cases of mothers with caesarean section

Interviewer: So you mainly work on mothers!

Respondent: yes, maybe . . .

Interviewer: What are the common illnesses that you have treated here?

Respondent: It is malaria and maybe respiratory tract infections and diarrhea but most especially much of the malaria and respiratory tract infections.

Interviewer: So how often do you get children presenting with sore throat, adults presenting with sore throat?

Respondent: We get them.

Interviewer: So tell me about your training in RHD; have you had any specific training in Rheumatic Heart Disease when in school?

Respondent: I was still in nursing.

Interviewer: But you had some bit of training?

Respondent: Yes.

Interviewer: And then, after school did you have any training about Rheumatic Heart Disease?

Respondent: Not really.

Interviewer: Any CME, seminars where they talk about it?

Respondent: Maybe the CMEs when we have some conferences in the field

Interviewer: But not RHD

Respondent: No

Interviewer: So in a month how many RHD patients do you see here in Buwambo?

Respondent: I have never seen any.

Interviewer: So when did you last see an RHD patient?

Respondent: I was still in training

Interviewer: And in which hospital was that?

Respondent: Mulago hospital.

Interviewer: So here you have never had any one.

Respondent: No.

Interviewer: And then umm, I am now interested in the things they taught you about RHD; so what is your understanding of the causes of RHD?

Respondent: A patient will come with complaints of sore throat and if not treated properly, it can send to the heart maybe and start complaining of heart problems.

Interviewer: And have you had such patients complaining about sore throat which is not normal?

Respondent: There are there.

Interviewer: How do you handle those patients?

Respondent: We give them some antibiotics, we start with oral if it's acute, and we give the IV injections and then continue with oral antibiotics, maybe capsules.

Interviewer: Do those patients come early or they usually present in late stages?

Respondent: They don't come early because we may ask the patient and they say, 'I've been swallowing some herbs' these native drugs.

Interviewer: So they first use herbs before they come!

Respondent: And at times it starts with flu, so they be like, 'I have been taking some tablets' maybe tablets with some Panadol

Interviewer: This one you have answered it. It was asking; are you aware of any link between RHD and sore throat? Are they associated?

Respondent: I don't know. I think there maybe but I wasn't aware.

Interviewer: So what were you told can be done to prevent RHD? What can we do?

Respondent: Maybe to give some health information to the public on how someone can approach the health worker very quickly so that she can get treatment early.

Interviewer: And then those that have not gotten RHD, what can they do to prevent it?

Respondent: I don't know.

Interviewer: Okay. And how can we treat RHD? What were you taught about the treatment of RHD?

Respondent: I don't know.

Interviewer: You don't know how it's treated!

Respondent: I don't know.

Interviewer: And then, if they offered training in RHD would you like it?

Respondent: Yeah.

Interviewer: Which areas would you want to?

Respondent: umm in that . . . where you can ask the patient, "have you had any past problems?" before giving medicine to that patient. I would like to have that training; to have some questions before you review that patient. It is also good to review the health of that patient.

Interviewer: Which other area would you want to be trained in as far as RHD management? Like what topics?

Respondent: Topics like respiratory tract infections, sore throat, even sore mouth; diseases to do with this system of maybe with the alimentary system.

Interviewer: So what is your understanding of the long term prognosis of RHD?

Respondent: Someone has a chronic heart which can even cause stroke.

Interviewer: Can RHD heal?

Respondent: I don't know but if not treated properly well it can cause heart attack which cannot be cured.

Interviewer: Have you encountered any RHD patients? You said here no!

Respondent: No.

Interviewer: Where did you encounter them?

Respondent: In Mulago.

Interviewer: So when as the last time you encountered an RHD patient?

Respondent: About thirteen years back.

Interviewer: Do you remember how that patient presented? What were the complaints?

Respondent: That had a disease that she complained about difficulty in breathing plus pain, that whenever she would sleep she would feel uncomfortable.

Interviewer: So how did you manage that patient?

Respondent: We referred that patient to the consultancy room.

Interviewer: During that time how many RHD patients did you see?

Respondent: I don't remember.

Interviewer: Were they many or few?

Respondent: They were few.

Interviewer: And if you look at their demographics; how were they? Where they children, adults?

Respondent: Some were children, some were adults.

Interviewer: But what were they mostly?

Respondent: They were adults.

Interviewer: Working or not working? Were they working adults or mostly at home?

Respondent: People who were mostly at home.

Interviewer: Do you think these patients know the link between sore throat, acute rheumatic fever and RHD? Do they know that those three are associated?

Respondent: No, they don't know unless they are taught.

Interviewer: So for the symptoms you said that they complained of chest pain and difficulty in breathing!

Respondent: Yes

Interviewer: How about their follow up did they come back when you told them to?

Respondent: Yes they would come back.

Interviewer: What would motivate them to come back?

Respondent: When they see they are still . . . they are not comfortable with the treatment, of course they come back.

Interviewer: What things motivated you?

Respondent: I don't have.

Interviewer: Did you have some that were missing treatment or missing appointments?

Respondent: Yes they were there because we would ask them, "Why have you not come back?" and they be like, "you see I had some problems" or "I didn't have transport and yet they are coming from far.

Interviewer: Okay, what else?

Respondent: 'I had some social problems at home.'

Interviewer: 'Social' like which problem?

Respondent: Like some problem at their home . . . I don't know how I can explain it. Someone might have an issue at home or a wrangles at home that she has to settle.

Interviewer: Did you have the drugs for RHD?

Respondent: No, we used to give drugs that were available.

Interviewer: Like which ones did you give? Do you know the names of the drugs that used to be available?

Respondent: Antibiotics

Interviewer: So for those are the barriers they were telling you; transport, social problems. So how about you; what do you think were the barriers they faced getting treatment?

Respondent: The drugs which are . . . maybe there needs to be more enlightenment in the CMEs to know how to treat the patient.

Interviewer: What else? What are the other barriers that you can think of?

Respondent: Maybe and some motivation

Interviewer: in what way?

Respondent: Some motivation in maybe transport

Interviewer: Do you think that when you give them drugs they take them?

Respondent: I think so; they take them because they are the ones who are suffering so they have to take them.

Interviewer: Now let us look at the local system barriers; we want to know which pieces are working for you and why you think so. Let's look at the administration; let's start with the district; is that one working for you as you do your work here? Do you deal with them here?

Respondent: No

Interviewer: But with other things when you are working, do you see the administration . . . does it contribute to you doing your work? Do you see it motivating you to do your work?

Respondent: Not much

Interviewer: Why?

Respondent: They don't give enough supplies, the drugs are not there and you have to explain to the patients, 'that drug is not there so maybe you have to go and buy it' and yet that patient doesn't have much. We have problem in our health centers IIs and IVs; those drugs are not there.

Interviewer: Where's the problem; is it the people who bring it in or its coming from . . .

Respondent: I don't know where the main problem is, but we put in the requisition but it doesn't come. I have been in the store but the drugs am supposed use have not yet appeared.

Interviewer: So what are you going to do with your patient?

Respondent: I will tell them my in-charge that we don't have drugs or maybe we look for another way we can anaesthetize the patient because there are those which can be available, for example when mothers are going for anesthesia, these days we use general methods but these days they are not available.

Interviewer: So what is your view about the administration within here? Is it working for you?

Respondent: [chuckles] I am always in touch with my in-charge. I request for drugs and if they are not there then, she says that they are supposed to be sent by the district.

Interviewer: So are you happy? Is it working for you?

Respondent: Not really.

Interviewer: Okay, if you look at the funding for health care is it working for you?

Respondent: No, but they have tried.

Interviewer: Where do they need to improve?

Respondent: In areas where we are finding problems, maybe in supply of drugs and others.

Interviewer: Apart from drugs which other supplies do you normally lack?

Respondent: Now some of the machines are down; they are not working because they are old so we need to replace them.

Interviewer: Like what machines?

Respondent: Our operating table has taken not even . . .

Interviewer: And what do they say? Do you raise the issues? What do they say?

Respondent: We raised the issue but they say they are still working on it, so maybe they need some time. So if we have a patient with a referral, we don't have the magnet although it is really not in good condition. Blood bank; we don't have access to the blood in case a patient needs blood.

Interviewer: What do you do?

Respondent: We really suffer, and indeed we have to get some mortality rates.

Interviewer: What is the nearest health you send them to?

Respondent: Of course we take them to Kawempe. It is either to Kawempe or Bombo Hospital, in the barracks.

Interviewer: And then when you look at funding for RHD, how is it? Is it working?

Respondent: Not really because I am not so much into technical issues.

Interviewer: How about the number of health workers; how are they?

Respondent: They are few, in fact we need some more. We need more staffs according to the numbers which are supposed to be in a Health Centre IV.

Interviewer: Okay, how about the qualifications of the health workers around? Do you have enough qualified workers?

Respondent: Yes, we have enough.

Interviewer: Do you have any cadre of a health worker who can work on RHD patients here?

Respondent: Maybe the medical officer.

Interviewer: How many do you have here?

Respondent: They are two.

Interviewer: And they are around!

Respondent: Right now they are not but when we call them, they come.

Interviewer: How is the waiting time for patients here?

Respondent: Waiting time for calling the doctor?

Interviewer: Waiting time before they see a health worker.

Respondent: They are always here in the morning and afternoon.

Interviewer: If someone came at 8am, what time would they leave, the outpatient?

Respondent: Processing a patient can take a long time; it can take like 2-3hours.

Interviewer: How about the quality of care; how is it here?

Respondent: That one I cannot [chuckles] . . . but we care for them.

Interviewer: If you are to gauge yourself, where do you fall?

Respondent: [laughs] I do like care.

Interviewer: Generally, the center, where would you put them? 40%? 50%?

Respondent: I cannot say it is 100% or 80% because everybody has his or her . . . but it could be 60%

Interviewer: What do you think has hindered the health center from moving from 60 to 100? What are those gaps that need to be filled?

Respondent: First of all the staffing, maybe even the distance because we don't have residential staff. Most of us come from far.

Interviewer: Okay, and then if you look at the medication do you think you have medication for heart failure? Do you have heart failure drugs?

Respondent: We have got this Aspirin and I remember giving it to those hypertensive patients

Interviewer: Do you have anti-coagulation drugs? Warfarin and the like?

Respondent: We don't have.

Interviewer: You don't have! By the way, health centers are meant to handle RHD?

Respondent: No, we settle acute rheumatic fever and we also handle those coming in for follow up for infections maybe and those kind of things. Maybe they need to be given their injections.

Interviewer: What injections? Do you have Benzathine?

Respondent: Benzathine we have.

Interviewer: Do you get patients who need it?

Respondent: We get patients with ARF.

Interviewer: How about RHD?

Respondent: That one I don't know.

Interviewer: How about the diagnostics here; do you think they are working for you?

Respondent: That one maybe you can ask the laboratory people; they are the ones who know about that.

Interviewer: But do you have echocardiography here?

Respondent: No, it is not there.

Interviewer: When you look at your medical records system, how is it here? How do you keep your records here? Are you satisfied with the way they are kept, the way you access them, the way information flows from in-patient and out- patient?

Respondent: They are not well handled because we do not have a medical records . . . eh, by the way it is there but the way it is handled is not good. It is not one that they can use. Sometimes you can look for records when they are lost.

Interviewer: And then do you have registers for ARF that you keep here?

Respondent: No.

Interviewer: You said you don't have those for RHD!

Respondent: Yes.

Interviewer: And do you have protocol and guidelines for RHD care?

Respondent: We have got these medical guidelines.

Interviewer: But do you know the referral path for RHD patients?

Respondent: No.

Interviewer: Which factor is working for you here? What are you happy with that you say this has enabled me to work?

Respondent: Generally we work on everybody who comes here but . . .

Interviewer: What motivates you?

Respondent: To work? Of course I have to work.

Interviewer: Okay. Let's look at the perceptions of patients' outcomes; do you think the patients get the care they need here?

Respondent: That is difficult; maybe you have to ask them

Interviewer: in your opinion

Respondent: Maybe we are trying, we are trying. If a patient comes and he doesn't get what she needs, he will go back home when he is not okay

Interviewer: For instance what can the patient go back without?

Respondent: of course we have to tell the patient to go and buy the drug

Interviewer: So if a patient with RHD came to Buwambo will that patient be handled here?

Respondent: We can handle first then we refer the patient. Maybe what I can add is that the medicine bought is little and when it is used up, we have to wait for some months. Like now we only have the Panadols

Interviewer: And you said you don't know where the problem is?

Respondent: I don't know.

Interviewer: Okay. If you look at patients' safety, do you think patients' safety issues are respected here?

Respondent: They are respected.

Interviewer: Why do you think so?

Respondent: Because a patient is a patient who comes and you have to handle that patient well, and confidentially.

Interviewer: So they are handled in a confidential way?

Respondent: Yes, like we have some special clinics like the ART clinic, we have some departments like the youth departments.

Interviewer: What can we do to improve the quality of care in our patients?

Respondent: Some improvement in areas like motivation and having CMEs.

Interviewer: Do you have the CMEs are not?

Respondent: We no longer have CMEs; we used to have them.

Interviewer: What happened?

Respondent: I don't know.

Interviewer: How was the attendance?

Respondent: The attendance was bad because when you call the people, the turn up would be low.

Interviewer: Have you seen any preventable death in a place like here?

Respondent: I don't know.

Interviewer: What could cause that?

Respondent: Maybe the patient may take long to get the treatment when the drug are not here and yet what he is suffering from can be treated

Interviewer: Okay, any other?

Respondent: That is it.

Interviewer: So in your opinion what are the two most important things Ministry of Health can do to improve the outcomes in our patients?

Respondent: Just to improve on the supervision and supply of drugs.

Interviewer: Do you get supervisions from like the district?

Respondent: Sometimes we get but maybe because of our rural places, they take long to come.

Interviewer: So when they supervise are your needs or issues raised?

Respondent: We raise them but they end there; they don't work on them.

Interviewer: Okay, so drugs and supervision!

Respondent: Yes.

Interviewer: Anything else?

Respondent: No.

Interviewer: And then at least you have seen the RHD patients, what can we do for them?

Respondent: So far we have not had any.

Interviewer: But in general because at least you have seen them somewhere, what can be done to make sure they can come for care?

Respondent: To get them their drugs so that they can take them

Interviewer: How can we help them to come for their drugs? What can we do to motivate them?

Respondent: Outreaches and advising them to take their drugs

Interviewer: Who should advise them?

Respondent: Any health worker

Interviewer: Anything just before we close?

Respondent: Now I thank you for coming, and after this, are you going to come and maybe give some assistance in that area of RHD?

Interviewer: Why we do this is we want to see the gaps because we can't fill them when we don't know where they are. That's why we come to health centers to get the different views to know what they don't know which is going to help us.

Respondent: Because we always have some supervision from the district, the municipality but these people are failing to come through our in-charge and I don't know why.

Interviewer: After these results are out, this will be the foundation to see which areas and which centers need to be boasted with learning. Thank you very much. Anything else?

Respondent: No

DATE	26 TH MARCH 20219
VENUE	BUWAMBO HEALTH CENTRE
STUDY PARTICIPANT	HW010 - Wakiso
SEX	MALE
AGE	█ YEARS
INTERVIEWER	

Interviewer: Thanks for allowing to talk to us but before we start I just want to you to know that whatever answer you give there's no wrong or right answer. We just want to determine how provide better to our RHD patients and then I want you to be frank and share your opinions the data we share is going to be confidential we will not link your identity to any of the comments you make so be free. Today is the 26th of March we are seated here in Buwambo health center. In which room?

Respondent: This office is for the in charge.

Interviewer: So we are seated in the in charge's office with one of the health workers in Buwambo.

Respondent: Yes.

Interviewer: Now sir, tell me about yourself. How old are you?

Respondent: I am making █

Interviewer: What are your qualifications?

Respondent: I first qualified as █.

Interviewer: How long have you been working here?

Respondent: I started in [REDACTED].

Interviewer: Okay and where did you train from?

Respondent: I Trained from [REDACTED].

Interviewer: So you said you've been working here for?

Respondent: For [REDACTED].

Interviewer: Let's look at the demographics of the patients you have seen in your practice. Tell me about them. Who are those people you have seen mainly? Age group, sex.

Respondent: According to the condition we are talking about?

Interviewer: Yes.

Respondent: Usually they are always adults; 16 years, 75 . . . 50-75years.

Interviewer: Those are the commonest?

Respondent: Yes. Male or female.

Interviewer: And what are the commonest illnesses you see in this place?

Respondent: Common illnesses; diabetes, hypertension, arthritis.

Interviewer: And among the children?

Respondent: Most conditions; respiratory infections (Upper and lower,) common colds, skin diseases. Those are the common illnesses in children.

Interviewer: Okay. Do you ever see any children who come with sore throat?

Respondent: I've ever seen, not just once or twice.

Interviewer: Is it a common illness around here?

Respondent: Not common but it comes with a season then it disappears. It's not so common.

Interviewer: Okay. Now let's talk about your training in RHD that's rheumatic heart disease.

Have you ever heard about it?

Respondent: I've ever heard about it just that I've not got many patients to handle.

Interviewer: So did you get any specific or special training during school in RHD?

Respondent: No.

Interviewer: Did they introduce that topic during school?

Respondent: They did.

Interviewer: They did?

Respondent: Yes.

Interviewer: Okay. And after graduation have you had any CME or any talk on RHD?

Respondent: I have just graduated.

Interviewer: Okay, so you have not had any training in RHD?

Respondent: No, I have just graduated.

Interviewer: You have just graduated?

Respondent: Yes.

Interviewer: When?

Respondent: In November.

Interviewer: Okay. So since you started practicing have you seen any patient with rheumatic heart disease?

Respondent: Yes. I had a patient when I was still a student. So that patient had rheumatic heart disease so we had to refer to Mulago heart institute; it was late.

Interviewer: So you had to take the patient to Mulago?

Respondent: I had to escort the patient to Mulago.

Interviewer: So did you manage that patient at all here?

Respondent: I wasn't here.

Interviewer: Where were you?

Respondent: I was in a different health Centre in Luweero.

Interviewer: So far have you seen any one?

Respondent: So far, no. The time I have been here, no.

Interviewer: You have not seen any one? Any RHD patient?

Respondent: No.

Interviewer: And then, so what is your understanding on the causes of rheumatic heart disease?

Respondent: The way I understand it originates from oral thrush (infection from oral thrush) then descends through blood to the heart valves.

Interviewer: Okay, and then are you aware of any link between sore throat and RHD?

Respondent: Yes.

Interviewer: And what's the link between them?

Respondent: The link?

Interviewer: How are they related?

Respondent: The same infection that attacks the throat is the same infection that descends through blood, attacks the heart then the patient will develop rheumatic heart disease. That's my understanding.

Interviewer: And then what were you told can be done to prevent rheumatic heart disease.

Respondent: Preventive measures?

Interviewer: Yes. How can someone prevent getting RHD?

Respondent: Oral hygiene, I think that's the first.

Interviewer: Okay. Anything else?

Respondent: And medical checkups can also help us.

Interviewer: okay. How do we treat RHD?

Respondent: In treatment?

Interviewer: Yes. How do they manage RHD?

Respondent: Of course for all patients with cardiac conditions we have to be in a specialized setting. Such a patient in place like Buwambo, we can't give a lot of management. We always tend to refer those patients.

Interviewer: Where do you refer them?

Respondent: To clinics where we know they can be managed well.

Interviewer: Do you know some of those referral clinics?

Respondent: we have new Mulago Heart Institute

Interviewer: Apart from Mulago?

Respondent: And other big hospitals.

Interviewer: Okay. Are there any aspects of RHD management in which you need to be trained?

Respondent: Yes.

Interviewer: Like which area? If you were offered to be trained in any aspect of RHD management.

Respondent: I want them to train me how to identify a patient with RHD because we study but we don't come out with that knowledge.

Interviewer: Okay. So in identifying patients!

Respondent: Identifying patients with Rheumatic Heart Disease and more training in management. Not just referring.

Interviewer: Okay. Any other area? So identification of symptoms and management!

Respondent: Yes.

Interviewer: Okay. And then so what is your understanding about the long-term prognosis of RHD?

Respondent: Long-term prognosis?

Interviewer: Yes.

Respondent: So long-term prognosis of RHD.

Interviewer: Yes.

Respondent: It can be due to other complications.

Interviewer: Any other?

Respondent: And maybe death as the final.

Interviewer: So you've told me that you have ever encountered an RHD patient.

Respondent: Yes.

Interviewer: So can you tell me; when did you last encounter an RHD patient?

Respondent: Last year.

Interviewer: Last year?

Respondent: No, October.

Interviewer: In October. So briefly summarize that visit. How did that patient present? How did you handle?

Respondent: The patient had a history of on and off fevers but had difficulties in breathing, and then he still had joint pains with swollen joints.

Interviewer: How was that patient managed? Did the patient come and present that I have RHD or came without.

Respondent: The patient came as an emergency, so we had to refer. We controlled the fevers but we had nothing much to do in that very moment so we had to refer the patient.

Interviewer: To where?

RESPONDENT: Mulago.

Interviewer: So you said since you started practice how many patients have you encountered with RHD?

Respondent: I got one patient.

Interviewer: One patient!

Respondent: Yes.

Interviewer: Okay. And you said how old was that patient?

Respondent: Was 64 years.

Interviewer: Okay and then when you look at these patients do you think they know the link between sore throat and this Rheumatic Heart Disease?

Respondent: They don't know.

Interviewer: Okay. And then what sort of symptoms do they describe to you when they come? In their own description, what do they say?

Respondent: They will tell you they always have difficulties in breathing, that's the first symptom, and then with fevers.

Interviewer: Any other?

Respondent: No.

Interviewer: Okay and then when you look at their follow up or when you tell them to come back maybe for follow up do they come back?

Respondent: Excuse me. I have only encountered one patient so I didn't get a chance of meeting her again.

Interviewer: Okay. So in your opinion I know you have not encountered any but what do you think stops some people from going into care? Now that one came as an emergency, but why do you think people don't seek care?

Respondent: People don't seek care just because of their ignorance; they don't know what to do and those who have tried to go for health care meet a problem of health care provider attitude.

Interviewer: What is it about the attitude of the health care providers?

Respondent: Because if I refer a patient to your unit and you don't attend to him or her, of course tomorrow that patient won't come back. I think that's the biggest problem.

Interviewer: Which other one? Why do you think you tell these RHD patients to come for treatment and they don't?

Respondent: And we have units which are very deep. And people don't have access to the health facilities, lack transport and such issues.

Interviewer: Anything else? How about your health care, what barriers do you face?

RESPONDENT: As in?

INTERVIEWER: when you are providing care, like that RHD patient who came and you referred.

RESPONDENT: yes.

INTERVIEWER: What stopped you from handling that case?

Respondent: [laughs] okay, lack of medical supplies first, then having doctors but we don't have medical drugs, equipment of course, so you have to refer.

Interviewer: Okay. Which drugs in that case would you need, that if they were here you would have helped that lady?

Respondent: (sighs)

Interviewer: You don't know?

Respondent: Yeah.

Interviewer: You can't think of any. Okay and then let's talk about the administration here. Is it working for you? Does it help you in any way when you are doing your work or makes your work better?

Respondent: The administration, though am learning it, in my view it doesn't help as I expect.

Interviewer: Where do you want them to improve?

Respondent: As Buwombo or from up?

Interviewer: Let's start from the district.

Respondent: From the district, for the better of our patients they don't do close supervision and then sometimes we have a lot of patients but we have few staff and even medical supplies we don't have. We don't have drugs.

Interviewer: Like which drugs are scarce here? Which are some of the essential drugs that you don't really have here?

Respondent: We don't have most of the drugs like, we don't have Hypertensives.

Interviewer: Okay. And do you have any drugs that treat heart disease?

Respondent: No.

Interviewer: Do you have any drug like Benzathine in stock here?

Respondent: I haven't heard but for the moment we don't have.

Interviewer: And you've said there's no supervision, supervision is lacking! How would you want your health center to be supervised?

Respondent: Of course if you come to ground as a head, you have to discover the problems; our issues, but those people may take a long time to come to the ground yet some of us have our issues so, it is such things.

Interviewer: Okay. How about the leadership here, if you need supplies and things to use do you get them?

Respondent: They do supply.

Interviewer: Anything lacking in the administration?

Respondent : [no response]

INTERVIEWER: silence means nothing?

Respondent: Let's leave that.

Interviewer: How about funding in health care, is it working for you as you are doing your work as a health worker?

Respondent: It's working for me on side but not much for the patients.

Interviewer: Okay. Explain more.

Respondent: Maybe we get funding but maybe we may not be knowing because I see we don't get most of the things we need. You find that one who has a BP machine moves with it; it's personalized. That means it's his and the health center doesn't have any.

Interviewer: So when you request what happens?

Respondent: Of course they keep on promising we shall get.

Interviewer: So what do you do when you get a hypertensive patient or people whom you need to check with that machine? In such instances how do you handle?

Respondent: But we always have our own equipments.

Interviewer: So you move with your own BP machine.

Respondent: [laughs] and when I am not around they won't take any blood pressure and I cannot leave it behind.

Interviewer: Umm, when you look at the number of health workers, how are they here? Are they working in number?

Respondent: We have a number of health care providers but I can say to an extent they are not enough. You know they may be enough but they don't want to provide services.

Interviewer: So how are the numbers of patients here?

Respondent: For the patients they know the time when we get drugs and when they are out of stock. When they know we have drugs they come in big numbers. Like in this season, we have a big number of patients not like the previous months.

Interviewer: They get to know there are drugs?

Respondent: Yes, that's when they come.

Interviewer: And then if you look at the qualifications of the health workers here are they working for you or there are Cadres where you feel like they need to be boosted.

Respondent: So things of Cadres, as you have seen we have doctors, nursing officers, clinical officers but you find a doctor doesn't work and it's the nursing assistant who works meaning those cardiac patients have to be attended by a clinical officer or a doctor or nursing officer but when you find a nursing officer attending to cardiac patients, that means doctors and clinical officers don't know what they are supposed to be doing.

Interviewer: When you look at the medicine you said you usually have stock outs. You don't have most of the medicine.

Respondent: Yes.

Interviewer: And for the heart medicine you don't have any. Is that what you are saying? Okay let me mention some; do you have some of the heart failure drugs here in your health center? Have you seen any?

Respondent: Am not sure.

Interviewer: How about the BPG?

Respondent: Am not sure.

Interviewer: Do you have Anti coagulation drugs in stock here?

Respondent: May be.

Interviewer: Maybe? Have you seen any?

Respondent: But I can't tell because I haven't seen any.

Interviewer: Okay. And how about diagnostics, tell me about them. How are they in this Buwambo health center? Are they working for you?

Respondent: The?

Interviewer: The diagnostics. For instance, do you have echo-cardiography here?

Respondent: No we don't have.

Interviewer: And where is the nearest health center to get one?

Respondent: Maybe in town or Bombo.

Interviewer: Okay. So let's look at the record keeping system and the health information flow here. Is it working here?

Respondent: As in what?

Respondent: Let's look at how you keep records in case you need to look up a patient who has

come in for follow up. Is it easy to access the file if you want to know who worked on that person?

Respondent: On my side it's working very well in the HAART clinic but this side I don't think it's flowing very well.

Interviewer: How can we improve the way information flows between you?

Respondent: Maybe installing a system where we can track all those patients.

Interviewer: What kind of system?

Respondent: It can be computerized.

Interviewer: Have you had any RF patients? Patients who come with acute rheumatic failure?

Respondent: I haven't had any.

Interviewer: So you don't have any kind of registers for those kind of patients.

Respondent: No. I know we don't have any registers.

Interviewer: Have you looked at any guidelines for RHD management?

Respondent: No.

Interviewer: Okay. Have you ever attended any CME on heart disease or RHD?

Respondent: I have never attended any CME.

Interviewer: Do you hold CMEs here?

Respondent: We have.

Interviewer: How many? How often?

Respondent: We always have. Of course for CMEs it always depends on staff cooperation; when you call someone to come and have a CME they say, "are you paying me? If you're not paying me, then I am not coming". Because some people are not cooperative so we can't have a CME of 2 or 3 people. With two people you can have it but of course it's better if you are more than 3.

Interviewer: Okay how often do you hold them?

Respondent: We always have CMEs twice a month.

Interviewer: And then could you be knowing a referral path for RHD patients; that this is where you take them. Do you know any of those facilities?

Respondent: Am not very sure.

Interviewer: So among the things we've have mentioned administration, funding, health records system, guidelines what has worked for you? What has motivated you to do your work? What do you think is working for you in Buwambo?

Respondent: Okay funding, administration, record keeping; actually everything is down.

Interviewer: Nothing has worked for you! Okay, and then let's look at the perception of patient outcome. Generally do you think these patients like the RHD patients get the care they need here?

Respondent: For those who find positive health care providers, they get the care.

Interviewer: Okay. And can your health center handle surgeries for RHD patients?

Respondent: Maybe you ask the doctor.

Interviewer: Okay. Do you have anyone who can handle such cases?

Respondent: I don't think.

Interviewer: You don't think?

Respondent: Yes.

Interviewer: Okay. When you look at your patients and their safety; is it put into consideration when you are working on them here in Buwambo?

Respondent: Safety?

Interviewer: Yes, for patients.

Respondent: Usually that's the first thing but in Buwambo I don't think it's considered. Somewhere somehow it's not considered.

Interviewer: Why do you think so?

Respondent: This is a center where you find the VHTs prescribing in the absence of staffs. So you can never know that they might prescribe a dangerous drug. So anything can happen.

Interviewer: Why does it happen? What makes that happen?

Respondent: I can't say that we don't have qualified staff because we have qualified staff, but people don't know how to perform their roles or when to perform their duties.

Interviewer: When you look at the quality of care being given to your patients here how is it?

Respondent: I think it's at 50

Interviewer: What's stopping it from being [100%](#)? Where are the gaps?

Respondent: Those people will prescribe a drug, the patient goes to the register but doesn't have drugs that means the chain is not complete. Some come to the laboratory but from there they are not seen by the medical staff.

Interviewer: Okay, anything else?

RESPONDENT: no

INTERVIEWER: Okay, have you seen any preventable death which occurred but wouldn't have occurred? You know there are those deaths that happen and you are like um no.

Respondent: It might have happened?

Interviewer: Yes.

Respondent: For The time I've been here I've seen only death that was at theater.

Interviewer: Where do you think went wrong?

Respondent: There I wont go deep.

Interviewer: I had to do with what? You don't have to mention people's names but what could have happened to her?

Respondent: Let's leave that.

Interviewer: We Leave that?

Respondent: yes.

INTERVIEWER:. Do you think patients are dying in the community without presenting to hospital for care?

Respondent: Of course.

Interviewer: Why?

Respondent: There are far away from the basic health care settings or they don't know what they are supposed to be doing.

Interviewer: They don't know what they are supposed to be doing, in what ways?

Respondent: In that when you are sick you have to go to the hospital where you can get help.

Interviewer: Which other reason? Why are they dying? Apart from distance and not knowing.

Respondent: (silence)

Interviewer: Okay. So in your opinion which are the two most important things Ministry of

health should do to improve patient outcomes? Let's begin from general patients then we will narrow it down to RHD patients.

Respondent: Ministry of health! What I know they are funding but they don't follow the accountability for their funds. That's what they are supposed to do so that such a health care unit cannot lack even a thermometer and yet we are getting a lot of funds.

Interviewer: So accountability needs to be improved.

Respondent: Yes.

Interviewer: Okay anything else?

Respondent: And regional supervision for health workers.

Interviewer: What can be done for our RHD patients?

Respondent: Firstly by recruiting qualified staffs for future conditions.

Interviewer: Okay. Anything else before we finish?

Okay. Thank you so much for your time and contribution towards this study, we shall your ideas to provide better services to RHD patients.

Respondent: You are welcome.

Interviewer: And we going to give you your money to pay for the time you spent away from your duties.

Respondent: actually we receive a lot of patients; we receive around 200 patients, all children and adults with different conditions.

Interviewer: different conditions like?

Respondent: the upper respiratory tract infections, malaria, hypertension, diabetic patients, HIV, those ones of UTI's.

Interviewer: what are the common age groups of the patients?

Respondent: I will not say there are common age groups but we see almost all patients from 0 up to around 85+

Interviewer: is it like these elements cut across the age groups, or there are some elements which are more particular, for example those below five?

Respondent: For those below five, its most commonly with RTI's and malaria, and then from five years to thirty, UTI's and the malaria. Then 35+ you find them hypertensive, some are diabetic and some of them have heart problems especially the hypertensive patients.

Interviewer: Okay, so tell me about your training on Rheumatic Heart Disease; have you received any specific training during school about Rheumatic Heart Disease?

Respondent: Yes, just when I was in class but there was not any actual training that was done.

Interviewer: but in class, did they teach about RHD as a course or as one of those conditions that patients usually come with?

Respondent: um it was just a lecture about Rheumatic Heart Disease.

Interviewer: it was just a lecture, like a one off lecture?

Respondent: yes.

Interviewer: Okay, so have you received any training about Rheumatic Heart Disease since you qualified in 2016?

Respondent: no.

Interviewer: you have not received any training, since your graduation!

Respondent: Yes.

Interviewer: So how many patients of Rheumatic Heart Disease do you often see here, maybe in a day, week or a month?

Respondent: In a day we may not see any but patients we find hypertensive are like three. There are some we get and we refer. Others when their sugars are high, we basically send them to Mulago.

Interviewer: so how many do you often see sometime maybe in a week or in a month?

Respondent: in a month we can get like one.

Interviewer: so are these patients usually out-patients or in-patients?

Respondent: they are out-patients.

Interviewer: they are out-patients, do you have an in-patient unit here?

Respondent: yeah. So unless those ones who come and are in critical conditions, we admit. We can make them, give referral treatment.

Interviewer: so they come in here, you admit them give them and give the care they need, then after you refer them?

Respondent: Yes.

Interviewer: Okay. So now, you as an individual, tell me; what's your understanding of the causes of Rheumatic Heart Disease?

Respondent: To me it is basically patients who have uncontrolled blood pressures, actually they poorly take their medications and their BPs have failed to be controlled, and those ones who are diabetic. They irregularly take their drugs or miss and sometimes when they come to the facility, by the time you check their sugar levels they are high. So you put them on treatments and when they feel better, they go back and relax.

Interviewer: what kind of treatment do you usually put them on?

Respondent: probably, for the DM patients, their sugars are high and they have been on oral treatments and if the orals have not worked, we subject with insulin. And if the sugars have failed to stabilize, then we can refer them.

Interviewer: Okay. Um, as a health worker, are you aware of the link between a sore throat and Rheumatic Heart Disease?

Respondent: sorry?

Interviewer: As a health worker, are you aware of the link between a sore throat and Rheumatic heart disease?

Respondent: A sore throat to my understanding, it could be maybe an ulcer in the throat and the Rheumatic disease could be possibly because of high blood pressure, or then failure of blood vessels where they actually become narrow and the failure to supply blood to the delicate organs.

Interviewer: Okay. So according to you, the link between a sore throat, it's an ulcer, and then RHD is where the hypertension comes in!

Respondent: yes.

Interviewer: But do you think there is a link between the two?

Respondent: there is.

Interviewer: and what do you think that link is?

Respondent: Okay, maybe she can tell you.

Interviewer: Okay I will tell you later. Now for example in class you had one unit about Rheumatic heart disease, so what were you taught can be done to prevent rheumatic heart disease?

Respondent: possibly caring for those hypertensive patients to avoid other causes like heart failures.

Interviewer: so we are talking about the treatment of hypertension!

Respondent: yes

Interviewer: So that is prevention, how were you taught to treat RHD?

Respondent: treating!

Interviewer: so we were talking about the treatment; what do you think is the treatment for RHD?

Respondent: Um, to me the treatment for RHD could be when you treat the cause then you are trying to stop RHD, probably the hypertensive urgencies; when you treat them, then you are preventing RHD.

Interviewer: so, are there any aspects of RHD management in which you think you need more training?

Respondent: yes, possibly the whole course.

Interviewer: the whole course! Be specific, like?

Respondent: managing those conditions especially Rheumatic.

Interviewer: so what aspects?

Respondent: for the hypertensive, that I can manage, but when it comes to the chronic, I don't.

Interviewer: so according to you, you feel that you need to study about the whole course and not just RHD management!

Respondent: yes.

Interviewer: so as a health worker what is your understanding about the long term prognosis of RHD?

Respondent: the prognosis is that they are put on late treatment and the care that those patients are given, the prognosis may be good but if the care is not good and the treatments, then the prognosis is poor.

Interviewer: so which means that the long term prognosis will be depending on?

Respondent: the treatment and the care.

Interviewer: Okay, thank you so much. So tell me about your encounters with patients of RHD; tell me how the last time you saw a patient with rheumatic heart disease was? Who was the last patient you saw of RHD and how do they present themselves? How was that visit?

Respondent: actually I have ever seen one patient and, it was HT clinic. It was in 2017 and he was having difficulty in breathing, tachypnea and tachycardia. He was over-sweating and his BP was high.

Interviewer: his BP were high!

Respondent: yes.

Interviewer: Okay.

Respondent: actually they could just refer that patient.

Interviewer: you just referred the patient! Was the patient an out-patient or in-patient?

Respondent: was an out-patient. Actually we were treating the patient before but it was an on and off treatment.

Interviewer: so what were you treating before?

Respondent: hypertension.

Interviewer: you were treating hypertension!

Respondent: yes.

Interviewer: not RHD as such?

Respondent: no.

Interviewer: Okay, so what is the average age of the RHD patients that you see here?

Respondent: 65+

Interviewer: 65 and above! Are they either working or not? Are they in school or not?

Respondent: not working.

Interviewer: they are not working! Okay, so which means they are 65 and above and not working!

Respondent: yes.

Interviewer: why is it that they are not working? Is it the disease process? Is it because of the age?

Respondent: some are saying age and others don't have work.

Interviewer: so do you think those patients are generally aware of a link between a sore throat, Acute Rheumatic Fever and Rheumatic Heart Disease?

Respondent: I don't know.

Interviewer: Okay, why do you think that they are not aware?

Respondent: because they have not been informed and not educated about it.

Interviewer: about the disease?

Respondent: yes.

Interviewer: so according to you, you feel that the patients are not aware!

Respondent: I think.

Interviewer: Okay.

Respondent: at least unless they can get CMEs, health talks and education and other health studies.

Interviewer: so what sort of symptoms do those patients of RHD describe?

Respondent: fatigue, then the palpitations, swelling of the lower and upper limbs and the varicose veins.

Interviewer: anything else?

Respondent: no.

Interviewer: so are those patients usually good about follow-ups and adherence to treatment or not?

Respondent: sorry?

Interviewer: are those patients, now like for example that one who came to the clinic, do they usually come for follow-up and do they adhere to their treatment?

Respondent: no. When they get better or when they feel fine, they don't come back. So they only come back when they get problems. That's when they come back.

Interviewer: so you are trying to say that the when the symptoms re-surface that's when they come back!

Respondent: yes.

Interviewer: anything else why they don't come back for follow-ups?

Respondent: I am not sure but to me that's what I think, because we only see them when they have a problem, but if they don't . . .

Interviewer: they don't come! So as a health worker, what sort of barriers do those patients commonly face or state to get the care they need?

Respondent: the distances they travel; the health facility is far from their homes, but then when they come, there are no drugs. So you prescribe and they go and buy. So drugs become a problem because what they stock is not enough.

Interviewer: so you are saying that some of them have issues of transport! You said that they stay very far from the health facility!

Respondent: yes.

Interviewer: and then the issue of drugs!

Respondent: yes. Someone says that I will go and then they write for me but I don't have money to buy the drugs, then they come here when the condition is worse.

Interviewer: Okay, so what sort of barriers do you perceive they face in getting the care they need?

Respondent: I beg your pardon.

Interviewer: according to you as a health worker, what do you perceive these patients face in getting the care they need, as a health worker?

Respondent: to me, I think the inadequacy of drugs that they stock.

Interviewer: anything else?

Respondent: that is what I think, maybe even the health workers to see the patients are not enough because you might find that one clinician or doctor sits here from morning to around evening and yet the patients are many. So you find yourself tired, and the patients over-wait, then they get tired and then someone goes away.

Interviewer: so the patients over-wait to see the clinician and the doctors!

Respondent: yes.

Interviewer: so they get tired and go!

Respondent: some are sent to the lab and they delay there; they spend a lot of time there because not only one patient is worked on. So someone gets tired from the lab and then just goes.

Interviewer: so when they tired from the lab, they don't come back to you?

Respondent: yes.

Interviewer: Okay, so let's look at the local system barriers. For example, now we are talking about Wakiso district, right from the district then to the hospital. So when we talk about administration and leadership to the district, what are the kinds of barriers that affect your work as a health worker, administration-wise and leadership-wise at the district?

Respondent: with communication, there is a gap.

Interviewer: how?

Respondent: at times there are things that happen, or they say that there will be a meeting and then they inform you that there is a meeting tomorrow, so they inform you today or you just see when they have lined up with the staff an urgent staff meeting. So some may be off and then they will just miss. Possibly me I think there is a communication gap.

Interviewer: administration-wise; what are some of the barriers that hinder you? Because now we want to find out the enablers, and barriers that hinder a health worker to do your work Administration-wise and leadership-wise. Do you think communication is only the issue?

Respondent: and possibly the supplies of drugs, because when they come to the district it takes long; they may take like a week or weeks when they have not supplied the facility and yet when these patients see that the vehicle has

gone to the district, they think drugs are supplied. So you will see them in big numbers and when you don't give them drugs, they say that you take them.

Interviewer: they say that you take the drugs?

Respondent: yes.

Interviewer: so which means that you're saying that when they see that truck, is it a truck?

Respondent: yes, the truck

Interviewer: the truck of . . .

Respondent: the medicines, because they offload first at the district and then the district supplies, so the supplies take time from the district.

Interviewer: to reach here?

Respondent: yes.

Interviewer: so which means that when the patients see those, like you said earlier, they presume medicines have come!

Respondent: and then you will see them in big numbers, so when they come and someone goes without drugs, they say that you haven't given them.

Interviewer: so here at Wakiso Health Center IV, what are some of the local health system barriers to funding for health care in general or RHD in particular? Are you aware of any?

Respondent: no.

Interviewer: do you know anything about funding for the Health Center IV.

Respondent: no.

Interviewer: you don't?

Respondent: actually the funding, what I know is about PHC.

Interviewer: about?

Respondent: PHC, that one the in charge.

Interviewer: that is PHC. What is PHC?

Respondent: those are the funds that are for the facility, like cleaning, preparing.

Interviewer: Okay tell me about the health workers; how are the numbers? What are the numbers of the health workers and their qualifications, and the barriers, as in; waiting time and the quality of care?

Respondent: possibly we have the nursing assistants or the nursing officers, the midwives, we have the clinical officers, and the theatre assistant, and the nurse but we don't have a psychiatric personnel.

Interviewer: Okay, what about the doctors?

Respondent: they are around.

Interviewer: like how many?

Respondent: they are two.

Interviewer: so according to you, are the health worker numbers enough?

Respondent: they are not depending on the patients we receive because you may find on duty, there is one clinical officer and one nurse, so the nurse is supposed to be here at OPD, then the in-patient and even at the in-patient wards.

Interviewer: you're saying that the nurse, on a shift you can have one clinical officer and one nurse!

Respondent: yes.

Interviewer: and the nurse is attending to OPD and in-patients and theatre!

Respondent: no, in the theatre there is a theatre assistant and the nurse. So what happens, those midwives sometimes help out in the theatre? When it comes to OPD and in-patient, you find one nurse on duty?

Interviewer: so according to you, are those numbers enough or not?

Respondent: they are not enough.

Interviewer: so what about the wait times, how long does a patient wait?

Interviewer: the waiting is not much, so it is dependent; if you have gone to the laboratory, it depends on the tests requested because there are some patients we see clinically, then they go to the table outside. After getting the number, they go to the dispensary and get drugs and then go. So it's dependent on the request you have made in the laboratory and how you see the patient.

Interviewer: what about quality of care.

Respondent: it is not bad.

Interviewer: why is it not bad? How do you quantify that it has not been bad?

Respondent: because you may see a patient and he or she tells you what, her problem is and then you treat accordingly. So I may say it's good and then you ask the patient and he says that it's bad.

Interviewer: so the health workers; are they all qualified to provide care in this healthy facility?

Respondent: yes they are.

Interviewer: so tell me about the medications in regards to RHD; do you have enough drugs for example Benzathine Penicillins, anti-coagulant drugs and heart failure drugs? Do you have all those drugs around?

Respondent: the Penicillins are there.

Interviewer: like which Penicillins specifically?

Respondent: Amoxicillin, Penicillins, Ampicillins.

Interviewer: what about Benzathine?

Respondent: it's there, but when they bring, they are few.

Interviewer: they bring few! Like how many and for which duration?

Respondent: because they bring every quarter, in a quarter they supply around 6000.

Interviewer: 6000 vials!

Respondent: and the patients we receive actually in a month are 1000 plus.

Interviewer: the patients you receive in a month?

Respondent: yes.

Interviewer: So you are telling me about the medications; you are telling me that for a quarter, they need like how many vials?

Respondent: 6000 and yet the numbers we receive are many.

Interviewer: the numbers of?

Respondent: as in the numbers of patients. And those ones we put on Penicillins are especially the children. So you may find that the ratio of drugs to patients is less.

Interviewer: so does that still work for Benzathine penicillin?

Respondent: yes, what they stock is not enough.

Interviewer: so what about the anti-coagulants drugs, the warfarin and heart failure drugs?

Respondent: they don't stock.

Interviewer: they don't stock them!

Respondent: the anti-coagulants.

Interviewer: but do you get patients who need them?

Respondent: yes, especially those ones who are on DVTs.

Interviewer: about diagnostics; what kind of diagnostics do you have here in the health facility or what kind of diagnostics do you do?

Respondent: we have the chemistry tests, the RFDs.

Interviewer: any others? Like ecocardiography, do you do them here?

Respondent: no, we don't. It's only chemistry.

Interviewer: only labs that you do!

Respondent: yes.

Interviewer: so the other diagnosis like X-ray, ecocardiography, those ones?

Respondent: we send them out.

Interviewer: you send the patients to be done from out.

Respondent: yes.

Interviewer: Okay, so tell me about health care information in the health facility.

Respondent: the what?

Interviewer: health information and medical records systems here; how are your medical records? Tell me about the registrars and how you store your patients' information here at the facility.

Respondent: we have HMIS book registers especially at the OPD and the dispensary. Actually every department has registers.

Interviewer: what is HMIS?

Respondent: they are registers where we find the out-patients and in-patients maybe in the lab . . . I was saying that maybe in the lab it is a computerized system but here it is in-patient and out-patients.

Interviewer: we were talking about health information, how is the integration of health information between the OPD the in-patients? How do you integrate your medical records?

Respondent: we have the medical records personnel

Interviewer: what does that person do?

Respondent: he collects data weekly and monthly and then he issues a report. We also have meetings, data implementation meetings done every month.

Interviewer: data implementation meetings?

Respondent: Yes

Interviewer: so do you have any in-patients and out-patients' registers?

Respondent: yes, they are there. The out-patients' are outside there, then the in-patients' is at the . . .

Interviewer: Okay, so do you have specific registers for specific conditions? For example, a register for Rheumatic fever, RHD, or a register for those other conditions?

Respondent: actually we have one register for all conditions; we don't specify registers or for UTI's or RTI's.

Interviewer: what about for hypertensives?

Respondent: those ones are there at the hypertension clinic.

Interviewer: so you are saying that the patients for hypertension also have their own register?

Respondent: yes, but the screening is done from OPD. So when you screen them, you put them on treatment for one week and then you send them to the hypertension clinic, but the screening is done here.

Interviewer: so you are saying that you have a general register of the OPD but you don't have specific register for example other treatments like hypertension and RHD!

Respondent: yes, apart from TB cases.

Interviewer: any guidelines and protocols for RHD care here?

Respondent: no, we don't.

Interviewer: do you have any referral pathways in receiving patients of RHD here?

Respondent: actually we have been referring them to Mulago.

Interviewer: so what is your referral pathways? When you receive them, what do you do before you send them to Mulago?

Respondent: in general, we just write a referral to Mulago (Hospital).

Interviewer: so tell me about the local health system enablers here; what motivates you as regards to administration and leadership? What motivates you to do your work as a health worker?

Respondent: Okay, the motivation may not be there so much, but me personally, I love what I do.

Interviewer: so, structure of the health system here enables you to do your work?

Respondent: yes.

Interviewer: Okay, it makes you to love what you do! Okay, so the funding of this health facility does, it enable you to do your work as a health worker, funding in general, and that of RHD?

Respondent: I reserve that question to the in-charge because I don't know how much they receive, and despite that, I am not a qualified or I am not paid, so I may not know.

Interviewer: so we are talking about enablers do the health workers. Do the numbers enable you to be able to do your work.

Respondent: the what?

Interviewer: the enablers as health workers; are your numbers enough to do your work?

Respondent: the health workers are not enough.

Interviewer: so which means they don't enable you to do your work!

Respondent: it's because you may find only one person as you may see, and they are calling me mostly. Especially we have these students here; they always want to consultant and you find that you are alone.

Interviewer: Okay, so which means that even the quality of care . . . tell me about the quality of care, as in regards to the numbers. Because now, you are alone; does it enable you to provide proper quality of care?

Respondent: Yes, for the patient we receive, you have to manage and give care to that patient because what is in your hands is the one you use.

Interviewer: so the drugs or the medications that are sent to the health facility, do you enable them or enable you to do your work so far?

Respondent: Actually, like I said, they are not enough. You may find yourself sending a patient to go and buy because they are not around.

Interviewer: so it is not enabling?

Respondent: yeah.

Interviewer: so what about the medical records system! Are they enabling for you to provide your care?

Respondent: there is no problem with the records system.

Interviewer: and you are able to access information in case you need records on the in patients!

Respondent: yes.

Interviewer: or for example, are you able to obtain that information from all the different departments?

Respondent: yes.

Interviewer: so you told me that you don't have guidelines and protocols for RHD, right?

Respondent: we don't.

Interviewer: Okay, this is my last question; perception of patient outcomes. Generally, do you think the patients get the care they need or not?

Respondent: me I thin they do.

Interviewer: you think they do! Why do you think they do?

Respondent: because we at least try our best so that we give what they need.

Interviewer: Okay, so you feel that you give them what they need!

Respondent: yes.

Interviewer: what about surgery?

Respondent: surgeries, they do.

Interviewer: what kind of surgeries do you do?

Respondent: C-section, hernia

Interviewer: Okay, tell me about patients' safety and quality of care concern.

Respondent: as in security?

Interviewer: safety, as in, as you provide your care as a health worker, are the patients safe and do you provide quality care or do you have any concerns with that?

Respondent: As we said, they have; we have out stocks, for example you may be giving service but you don't have gloves and yet you see that the patient needs service from the health worker.

Interviewer: so do you think the patients are safe?

Respondent: actually the patients are not safe.

Interviewer: Okay, and what about the quality of care?

Respondent: I think the quality is fine.

Interviewer: have you had any preventable deaths here at the health facility?

Respondent: the?

Interviewer: preventable deaths, have you had any here?

Respondent: as regarding?

Interviewer: preventable deaths, for example, we have patients who die or patients you lose but then the health worker would have prevented that death.

Respondent: yes, they are there.

Interviewer: why do you think?

Respondent: lack of what to use.

Interviewer: lack of what to use, as in?

Respondent: now for example, you might get asthmatic and you don't have oxygen, and you have the skill but you end up losing the patient.

Interviewer: any other scenario you have had around here?

Respondent: now for the accident patients, you have the knowledge of what to do but you will see the patient dying because you don't have what to use.

Interviewer: so do you think patients are dying in the community without presenting to the hospital for care?

Respondent: yes they are there.

Interviewer: why do you think patients should be dying?

Respondent: first; they don't have what to bring them here, as in regards to transport. Then two; someone thinks I will go to the hospital and be told to buy this and that because it is not there, so as a result they stay at home.

Interviewer: anything else?

Respondent: there are some who don't have caretakers! I So you think; when I go to the hospital, they will ask me that you are admitted but do you have anyone to look after you? So he stays home because of that.

Interviewer: Okay, thank you so much. So what in your opinion the one or two most important things ministry of health could do to improve patient outcomes?

Respondent: one; stocking enough drugs; and then supervising health workers.

Interviewer: supervising health workers, anything else?

Respondent: and motivating.

Interviewer: what kind of motivation are we talking about?

Respondent: in terms of support, or it can be quarterly. They can say we are giving sugar or say that we shall take or give lunch to the health workers.

Interviewer: Okay, anything else about motivation?

Respondent: then the payments and calling health workers for training because sometimes they do organize workshops but as I said, the communication is poor. You find that one health worker goes for a workshop over and over again and others are not gaining.

Interviewer: Okay, thank you much for your time.

PARTICIPANT ID	HW012 - Wakiso
DATE	
VENUE	UHI WAKISO DISTRICT
AGE	■
INTERVIEWER	

Interviewer: This is a qualitative study. So basically, as I have given you the consent form, this study is to determine how to provide better care for Rheumatic Heart Disease. It is building a case to invest in Rheumatic Heart Disease and control in a limited resource setting and as you know, when we are doing research there are no right or wrong answers. We just need to know what happens on ground. So please be frank and share your opinions. The data we gather is confidential; we won't link it with your identity to any of the reports we produce. So tell me about yourself; age, qualification and your training.

Respondent: I am [REDACTED]

Interviewer: Where did you train from?

Respondent: [REDACTED].

Interviewer: Okay, thank you so much. How long have you been qualified?

Respondent: Its now [REDACTED].

Interviewer: And how long have you been working in Wakiso Health Center IV?

Respondent: I have been here for [REDACTED].

Interviewer: [REDACTED]?

Respondent: Yes.

Interviewer: So you have been working at Wakiso for [REDACTED]!

Respondent: Yes.

Interviewer: So tell me about the demographics of the patients you see in practice and the commonest illnesses.

Respondent: We see patients from neonates up to old ages but we commonly see patients with upper respiratory tract infections, infections which cause fevers like malaria and skin infections normally in OPD. But we have certain illnesses that are separated, like non-communicable diseases like hypertension and diabetes on different days. We have an HIV clinic where we see clients and we have a post-operative ward where we do Caesarian sections. So we do most of

the cases and those we can't isolate, we refer to higher places where they can get better specialists.

Interviewer: These patients that you see, tell me about their age groups; what specific conditions are common in different age groups? For example, 0-5, the young ones and teenagers. What common illnesses are in the different age groups?

Respondent: Commonly, if I start with the neonates, it is normally neonatal sepsis. Then outside neonatal period, 1 and 2 months to 5 years, they commonly present with upper respiratory tract infections, pneumonias, cough, and then sometimes with other fever conditions like malaria and febrile convulsions. Then from around 6 years to 15, they normally also present with upper respiratory infections, cough sometimes those fevers, flu and malaria. Then the adults like I told you, we have many with HIV, so there's no separate group of ages. With hypertension, our patients are always above four years and we also have a few with diabetic children. I think we have one day a week where we carry out DM clinics; we can have one or two in a week that we see, so we find that most of the hypertensives are about 40 years. HAART clinic is general, then as I told you, the labor suite are normally for mothers.

Interviewer: Okay, thank you so much. Tell me a little bit about your training in Rheumatic Heart Disease; have you received any training in school about Rheumatic Heart Disease?

Respondent: It was not specific, just the normal lectures. There wasn't anything specific about it.

Interviewer: Okay, was it like a course unit or it was like when you do a problem based learning where they give you a topic to research on? How was it?

Respondent: Some topics I can't remember what we did for that, but I do remember we did problem-based and others in lecture, but I do recall we covered that although am not sure if it was under problem-based or lecture.

Interviewer: Okay. So since you graduated, have you received any training in Rheumatic Heart Disease?

Respondent: No.

Interviewer: You haven't!

Respondent: We haven't.

Interviewer: Okay, so in Wakiso Health Center, how many patients with Rheumatic Heart Disease do you often see in maybe a day, week or month?

Respondent: Particularly for the time I have been here I have not diagnosed any patient with Rheumatic Heart Disease. It's not that I have not seen, I just can't confirm. But it takes time to diagnose that kind of condition because sometimes you feel that someone has heart anomalies, irregular heartbeats but then you have to refer that patient for confirmatory; you can't just diagnose that this is Rheumatic Heart Disease because maybe of some abnormalities like irregular heartbeat. There are other things you have to investigate and confirm to get the diagnosis.

Interviewer: In training where you able to see any during your training?

Respondent: Yes.

Interviewer: During?

Respondent: My internship.

Interviewer: You saw but since you came in Wakiso you haven't seen any specifically?

Respondent: Yeah, I have not seen to confirm to myself that without reasonable doubt this is Rheumatic Heart Disease.

Interviewer: Which means that they have the symptoms but you have not yet confirmed that they have Rheumatic Heart Disease?

Respondent: Yes.

Interviewer: Are those in-patients or out-patients?

Respondent: Out-patients.

Interviewer: They are usually out-patients! Okay, thank you so much. Now, as a medical officer what is your understanding on the causes of Rheumatic Heart Disease?

Respondent: The way I understand Rheumatic Heart Disease; it mainly starts with infections in the group A Beta-hemolytic streptococci which affects the upper respiratory infections, then leads to auto-immune reactions which affects the heart which then causes valvular problems, which are micro and then you get micro deficiency, then stenosis, and then end up with heart failure.

Interviewer: Okay. You as a health officer, are you aware of the link between sore throat and Rheumatic Heart Disease?

Respondent: Yes please.

Interviewer: How do you know that link?

Respondent: Because the group A beta streptococci I have talked about will affect the upper respiratory tract infections so the body in means of trying to eliminate the bacteria, it will also cause an effect on the valves of the heart. So it will be an auto-immune reaction because the body will be the one destroying the valves as it tries to destroy bacteria from the throat so then you get problems from the valves.

Interviewer: Okay, thank you very much. So, what were you taught can be done to prevent Rheumatic Heart Disease?

Respondent: So, me what I remember is, one; treating the upper respiratory infections as fast as you can by giving proper diagnosis and giving antibiotics to patients. Then after that diagnosis of Rheumatic Heart Disease, maybe we can give them prophylaxis antibiotics like pen-v, like penicillin-V to the patients for a specific period of time depending on the stage of presentation of the patient.

Interviewer: Anything else?

Respondent: That's what I know.

Interviewer: Okay, so according to you, what can be done to treat? What were you taught can be done to treat RHD?

Respondent: First all treatment depends on presentation of the patient after doing your confirmatory tests, so you have to treat to eliminate the bacteria itself. For that one, you give penicillin-V and then also benzyl penicillin can be a start dose. Then if someone has presented with urethritis, then you can give anti-inflammatory like acetyl salicylic acid and then that's when you can give the dose of steroids. Then if it presents with pericarditis, then we follow the protocol of heart failure and manage according to what the patient has presented. Then if someone has presented with St. Peters rash, then you give anticonvulsants like sodium vulgate. If it fails, you can go to Pen-do and then give preventive measures thereafter.

Interviewer: Okay. Now are there aspects of Rheumatic Heart Disease management in which you need more training?

Respondent: Yes.

Interviewer: Like which ones?

Respondent: One; diagnosis.

Interviewer: Explain diagnosis. Which specific part of diagnosis do you want training in?

Respondent: In diagnosis, some of the symptoms we might be talking about them but we have never appreciated them to the patients, and sometimes you may see them but not know that they are the symptoms we are talking about, like the St. Peters rash. I have seen some in videos but not on a patient myself, so if you get maybe a patient and you look at it, because you may be seeing them on a patient but you don't know that it's what you have been reading about. Maybe the skin presentation; I have also never appreciated it on a patient. I mainly base on the history and yet sometimes patients have even forgotten if they had an upper respiratory infection. I base on history like heart irregularity and then I send for more investigations. So at least if I get more training in those symptoms of the patients, then it can be good for me.

Interviewer: What other diagnostics do you need training in to help you as a health officer?

Respondent: Interpretation of the ECG. I know a bit but I need more on how to interpret those electro-cardiograms so that I can relate them to the presentation of the patient.

Interviewer: Anything else, maybe about the x-ray or echo-cardiography?

Respondent: Yes maybe just x-ray you can. They all present with cardio-maggoty because I know people who have been in this field; the people of heart institute know features which can help you to interpret. So at least if someone can equip you with the skills on how to diagnose a person, then it can be easier for you to do others.

Interviewer: Okay, so according to you, what is your understanding on the long term prognosis of RHD?

Respondent: The long term prognosis, I think sometimes it's poor.

Interviewer: Why poor?

Respondent: It is a poor, one; because sometimes when you have Rheumatic Heart Disease, you end up with heart failure and the prognosis of heart failure, we know it's almost around five years depending on the stage of heart failure, which is sometimes not good. Two; most times we the health workers may not give the proper care and advice because you find that they are supposed to take prophylaxis, but you find most them are not taking prophylaxis as they are supposed to. Sometimes it's on patients; you tell them to come for injections but . . . because, I remember during my internship in Masaka you could tell the patient to come back for injections but wouldn't come back or even come back after two years only to tell you (by the nurses), "we told that patient to come for injections but now he has come back after two years with heart failure!" So probably it can be the disease itself and sometimes we health workers can contribute due to lack of knowledge. Then it can be patient-based if he has not done what he is supposed to do or take advice seriously.

Interviewer: Okay, anything else?

Respondent: Um, yeah I think if everything is done in the correct way, we can have a good diagnosis if we follow what we are supposed to do.

Interviewer: Which is?

Respondent: Like, if you do early diagnosis of the patient, then initiate what you are supposed to do like counseling and prophylaxis of the anti-biotic you are supposed to give to the patient. I think we can try to stop the poor prognosis of the patient.

Interviewer: Now tell me about your encounters with patients with Rheumatic Heart Disease; that is, in training and at your work place. Do you remember the last patient you saw and how was that visit? How did this patient present?

Respondent: The last patient I saw with rheumatic was during my internship. That patient came with heart failure and I think that's what the patient was talking about were signs of heart failure; difficulty in breathing, swelling of the lower limbs and arthritis. Otherwise, we were just managing it as a heart failure by that time.

Interviewer: Okay, the patient already had Rheumatic Heart Disease, so you were treating the complications!

Respondent: Yes.

Interviewer: So what do you think has been the average age of those RHD patients you have been seeing? Where they working, in school or not?

Respondent: I can't remember whether they were in school or not but at least the two patients I have properly seen that they have heart failure, because I have seen heart failure secondary to Rheumatic Heart Disease, both of them were less than twenty years old. One was around 15 years and the other girl was around 18 years, but less than twenty, around there.

Interviewer: So do you think those patients are generally aware of the link between sore throat, acute rheumatic fever and Rheumatic Heart Disease?

Respondent: I don't think they are because even some health workers don't know, so I don't expect those patients to be aware.

Interviewer: So you think the patients don't know because the health workers are not aware?

Respondent: Yes. Because, most times like the way you see Uganda, they are not like those countries where patients read a lot. There are a few patients that can read a lot because it's us who read and give that information to patients, so if you find that 30 of us are not aware, then

you expect around 70% of patients are not aware. First, they should empower us the health workers and then we can empower the people.

Interviewer: So just to remind me, what kind of symptoms do these patients describe when they come in? Those you saw, you told me they came with heart failure?

Respondent: Yes.

Interviewer: Difficulty in breathing?

Respondent: Difficulty in breathing, Apnea, couldn't sit on bed, swollen limbs, swelling, abdominal distension and arthritis. That's what the patient would tell you but when you check, you get irregular heartbeats.

Interviewer: So according to you, do you think those patients are good to follow up and adherent to treatment? Were they good to follow up?

Respondent: Yes. They must be followed up.

Interviewer: But do they go for follow-up?

Respondent: No, the health workers or patients?

Interviewer: The patients.

Respondent: They don't, that one I can't lie to you whether they follow the treatment prescribed or not, but during the hospital we could try, but when you discharge them you don't know.

Interviewer: Which means you are not aware if they are adherent to treatment or not?

Respondent: Yes.

Interviewer: And it means the one whom you told me came in after two years and if you did an earlier follow up, they were not able to come back on that follow up date!

Respondent: Yes, the challenge which I saw is if you follow in the medications they were taking, you find that they weren't there. Then if the medication is not there in the hospital then why would you follow up a patient in the village if they are telling you they don't have money to buy the drugs? Sometimes you find that you need a medication but the patient has to go and buy at the pharmacy, so the challenge begins exactly at the hospital.

Interviewer: So what sort of barriers do the patients commonly state to getting care they need?

Respondent: The first one is about seeing health workers. In Uganda, seeing a health worker is not easy except if the health worker also left. Coming here, you realize that someone is in line, like that one with a heart failure must go to OPD and yet he has difficulty in breathing, so he is seated in a chair and is going to wait for 5 hours when nobody has seen him. So I think what we have to improve is, I don't know how we can do it, but it is the health worker to patient relationship or our attitude at places of work. Because, you find that sometimes there are many people and there's only one person and in some places you find that there are no doctors. Sometimes you find patients have to travel long distances. Leave alone Kampala where there are many health centers, but when you are deep in the village, someone tells you I need to use 20,000shs - 30,000shs on boda to come to the hospital, but then he reaches and there's a problem getting medication. So he decides, "next time let me try my herbal medicine and see'

Interviewer: Which means we as health workers become barriers to patients coming to seek treatment and our attitude also towards patient management!

Respondent: Yes, that one is very true because I experienced this one time: I had a man with heart failure and needed an x-ray but even before writing an x-ray, even reaching there alone is a problem. He can't even move 5 steps! So sometimes you don't even have couches at the hospital to carry patients. So you reach there and the people want money to do the x-ray, which is government thing by the way! They even chase them from there, so you just find the man puzzled on the way and doesn't know what to do because our attitude is a big challenge, before you even look at other things.

Interviewer: So that is what the patients usually tell us. So now you as a health worker, what sort of barriers do you perceive these patients face in getting the care they need?

Respondent: First of all, sometimes they tell you or you see the same problems but some of the barriers are about medication; we totally lack medication, not only for heart failure but also in other conditions. An example I can give you is that sometimes in a health center like this, we might have obstructed labor and you don't have these anesthetic drugs here, gloves, not even a syringe or even a bottle of normal saline, but you are there and you can work. So patients come to the hospital, for example, I was in Kiryandongo some three years back and you could get patients with arthritis and much as you want to give them some furosemide, it's out of stock in the hospital. So the biggest challenge is medicine, and it chases away patients because when the patients come to the hospital, there is no medication. So one stays there for a week and you tell him to buy furosemide, but you find out that he doesn't even have food to eat. He won't come back because he sees there's nothing in the hospital, because good you diagnosed, but you haven't given me anything! You say that I am hungry but you don't give me food, so why should I come next time? Two, workload for health workers; you find the workload is too much. I can give you an example of OPD; he has to see more than 100 patients, so most times he stops listening to patients' problems. He just says; what is the problem, headache? It needs time to diagnose most of those illnesses and understanding patients' problems but if the patients are

many, then you will stop looking at most of the things. Just taking the pulse can tell you about the patient's case even if the patient hasn't told you anything, but if you have 100 patients, you can't have time to look at someone's heart because they are all complaining and you can't chase them. So you have to look at them all.

Interviewer: So tell me about the local health system barriers for example, what are the factors you usually get as regards to administration and leadership at the district in your provision for care? Like, by the time you get to the hospital, the administration should have done so and so. So what do you think is the barrier in the administration that hinders your care to the patients the way you would have done it?

Respondent: Maybe for me, if I talk about the leadership, the challenge I get is the way they deliver medicine to us. Most times I think we are not involved properly; you find that the drugs they deliver are most times not the exact drugs we want for certain conditions, because I think they should be delivering drugs according to the conditions we see in the unit. But sometimes, you find what they pack for a health center in Kimwanyi is what they pack for Wakiso, but I don't believe we see the same conditions. Because, sometimes you find we have drugs for conditions and they are getting expired yet you don't have these conditions, and they will do the same next year in excess. The other problem is between political leaders and health workers. Like, we have more of those health centers so the politicians don't get time to come to the health unit to understand how the unit runs or works but then they misinform the public. So instead of coming, they (public) just hate the facility because of what the politicians have said. They can come and tell health workers that everything is in the hospital and that you shouldn't buy anything when they have brought only two boxes of gloves in the theater which are even going to . . .

Interviewer: Those are politicians saying that?

Respondent: Yes. Like when they have been making tables (kimeeza) and they talk to the patients.

Interviewer: A 'kimeeza' is like a political rally!

Respondent: It's like a political gathering in the community and they talk a lot of things, but instead of coming to the health unit first and understand such that when you make your 'kimeeza', when people bring up something then you react with information on the ground. But for them, they react and make comments without coming on ground to find out what's happening to the facility. You find that you don't have things to use but people can't believe because for them they saw a track bringing in medication, and yet you are telling a patient to go buy something. So it becomes a problem to us to do our work, not only in RHD but generally.

Interviewer: My next question is funding for health care in general and Rheumatic Heart Disease in particular; are you aware of any funding in the health facility for the different health conditions and Rheumatic Heart Disease in particular? Are you aware of any funding in the hospital?

Respondent: Yeah. Generally, it's a government hospital where we work so most of the things, the drugs and payment of the workers comes from the government. But we have other stakeholders that help with other things, like for HIV, it is Mildmay. Then there are these non-communicable disease like hypertension and diabetes; I think they are for the Uganda Virus Research Institute. There's IDI that deals in circumcision in the unit.

Interviewer: IDI is Infectious Disease Institute?

Respondent: Yes, they help us with circumcision but with Rheumatic Heart Disease, it might be there but I haven't heard about that.

Interviewer: So you have not heard about funding for RHD?

Respondent: No, I haven't heard.

Interviewer: So about the healthcare workers, tell me about the numbers; how are the barriers of their numbers, qualifications and the quality of care they provide? How is it a barrier to provision of care? Do they provide the quality of care that's needed for workers?

Respondent: Those ones we have.

Interviewer: How about the numbers?

Respondent: They are few compared to patients. I think because the number of people who are supposed to be in health centers was paused before and people have not taken time to review, for example, our midwifery unit has three qualified midwives to work there, but that's where you have a post-operative where you have expectant mothers, antenatal care which can get more than 80 mothers a day and a labor suite which can deliver more than 5 mothers a day. So you have a very busy ward. Now if you have three (midwives) and one is at antenatal working on 80 mothers, do you expect her to take the correct thing even if she's qualified? You have one in post-operative, one in labor suite with two mothers, then who do you think is working at night and who is going to be off? That's one of the biggest challenges. So when you go to other departments, like I told you, we currently have 2 medical officers in the unit and two clinical officers. We have a theatre which is operating and it's very busy, then we also have non-communicable diseases. So this means that some units where there are supposed to be a medical officer, you just get a nurse to be there and yet you wanted someone more than a nurse to be there. So we have limited numbers.

Interviewer: So what you are saying is that with the few numbers of health workers, it affects the quality of care you give to the patients. Although they are qualified, they are few and this means that the quality of care they give to patients is poor because of the patient numbers.

Respondent: Yeah.

Interviewer: So what about the waiting time?

Respondent: It depends on the unit where you are. As I told you, at the out-patient department it will take some time because you may find two consultation rooms and yet the patients are many. So you have to take a lot of time; there's no doubt about that. Another challenge is that if you are in other departments, even what to use is a problem! Like I told you that if I need to do something, I need to tell a patient that you go and buy this, and then they say I don't have money.

Interviewer: So tell me about the health system barriers in regards to medications. You were telling me about medication particularly benzyl penicillin, anti-coagulation and heart failure drugs; do you have them?

Respondent: Yes, we have. Like for example, benzyl penicillin, but it gets out of stock sometimes. They do bring for us but after sometime we run out of stock.

Interviewer: Which means that they give you a good number to handle your patients? You have no issues with that?

Respondent: The issue with what?

Interviewer: With all the drugs.

Respondent: For the issues, we have. Maybe those of family planning don't have (issues), but the rest do. For family planning and ARVs, the drugs are ever there.

Interviewer: What about the anti-coagulants?

Respondent: I have not seen anti-coagulants in our unit.

Interviewer: Which means that's a hindrance! Like, when you get an RHD patient there will be no way to provide care without those medications!

Respondent: We just refer.

Interviewer: That's a Health Center IV for goodness' sake, so for someone to come to the heart Institute, they would have to get the initial care they need before they reach there. Sometimes they get sick in the night, you have those kind of things at least they need they such that they get the care they need.

Respondent: Indeed, they get it.

Interviewer: So tell me about diagnostics for example the cardiography and those other types of
...

Respondent: First of all, we have the laboratory so it's good we can do all things. But for these things of culture, we don't do.

Interviewer: Culture and sensitivity?

Respondent: Yeah, we don't do. ECG, even a mere ultra sound we don't, or even the ECG I can't even comment now!

Interviewer: Do you have an Echo Cardiography?

Respondent: No, we don't.

Interviewer: Then that's also a barrier!

Respondent: Yeah, that's what I told you that when I get a patient and I feel they need it, I write and tell them to go and do ECG.

Interviewer: So tell me about the health information system at the hospital; how are those systems interlinked? Okay, tell me how the medical records system is generally. How is your record keeping? Do you have a register where you keep them or an electric way of saving information?

Respondent: I think record keeping is good because they particularly have a person who is supposed to do that in the unit, and then every unit has a book in which they record each and every patient they see all their demographics, diagnosis and treatment they have given and the registration numbers of a patient. Then data is got by that records person, summarized, saved electronically and then at the end of the month, he has to give a summary of what the patients we have in each unit and conditions, and then sends to the district. So I think the record system is not a big issue.

Interviewer: You said every different unit has a book where they register the patients!

Respondent: Yes.

Interviewer: Are those different medical systems interrelated or integrated in a way that you are able to access information from the different units?

Respondent: Yes, you can access information from that unit although I have not seen people trying to access it a lot, but if you want it's there.

Interviewer: So do you have specific registers for specific conditions? For example, patients who come with hypertension and DM, do you have specific registers for them?

Respondent: Yes, like we have a specific register for TB. Like I told, we have non-communicables, so the book is there.

Interviewer: What about registers for acute rheumatic fever and Rheumatic Heart Disease? Do you have those too?

Respondent: I don't think so.

Interviewer: You don't think so, because you have never seen them?

Respondent: Yes, I have not seen them because I would have seen them if they were there.

Interviewer: Do you have guidelines and protocols for Rheumatic Heart Disease at the hospital?

Respondent: No, it's not there?

Interviewer: So what are your referral pathways in case you have received a patient presenting the symptoms you have described?

Respondent: When I get a patient, I just refer directly to Uganda Heart Institute.

Interviewer: [laughs]

Respondent: Because for me I am close, but if I was far I would send to a regional referral hospital. At least it's in Wakiso where I know you cannot get any disturbances.

Interviewer: Now, I need to know about the local system enablers; what motivates you to come from wherever you come from to work?

Respondent: The most important thing is the calling, and when the patients improve, there's a way it feels in the heart; you feel so happy. Other things are additional but the important thing is seeing the patients feeling better. Because, you can't treat a baby of four months but if you see the baby who had convulsions and fever improving, you feel so nice. In addition to that, our administration doctor who works for us is a very good man and very welcoming. You have to talk when you have a problem, so we work as a community and when at work, you feel like you have reached home. There's no big issue in the unit.

Interviewer: Which means the leadership at the hospital has enabled you to be able to provide your care!

Respondent: Yeah.

Interviewer: And has the district done the same?

Respondent: Even the district has no big issues. Normally we take long to communicate to the district, but it's mainly the in-charge who communicates to them if there's a problem and they will communicate if there's a way to solve your issues in your place. Even when they are not around, they have been able to solve our problems.

Interviewer: So according to you, do you think the general funding enables you to provide the care that you need to the patients?

Respondent: No, they are not because funds have to be pushed first in training those health workers. Because now, patients with rheumatic heart failure and fevers may be bypassing the health workers but maybe the health workers can't recognize. So there must be specific funds for training health workers to understand, and also put the diagnostics in place to help the patients because if these two are not there, you might think that you have no rheumatic heart patient in Wakiso when you have like ten of them!

Interviewer: So what you are saying is that to you, the funding is not enough!

Respondent: Yes.

Interviewer: So, I was saying the health worker numbers, are they working for you?

Respondent: No, they don't. Like I told you, we are few. Someone can come here and say that they are sick or that he left home with severe headache but he has been sitting here.

Interviewer: So you are saying the health care numbers don't enable you to provide the care the way you need to!

Respondent: Because, for example, you may go to the unit when the doctor doing the operation hasn't reviewed the post operatives and yet he has those he operated on back for review, and then they are called to the OPD because sometimes they call you when they have a patient but you sometimes fail to go there because you may find that you have five caesarian sections. So you tell them I will come but by the time it is seven, you have to go home, then you say I didn't see the patient which they called you for.

Interviewer: Which means the numbers also affect your quality of care; they don't enable you to provide the kind you want!

Respondent: True.

Interviewer: Do you think the medicine provided to the facility like Health Center IV enable you to provide your work the way you want to as a health worker?

Respondent: No. Maybe if you have that benzyl penicillin, you can start somebody on that antibiotic as you refer the patient, or you may give a prophylaxis. When the patient has received treatment from somewhere and they refer to us, we can give that continuous prophylaxis but as I told you, the challenge comes when the drug is not there because the patient can find no drugs on the unit.

Interviewer: So the health information systems, do they enable you to provide the care you need?

Respondent: With that one, at least there are no big issues.

Interviewer: So you told me earlier that you don't have guidelines and protocols of Rheumatic Heart d

Disease!

Respondent: In the hospital, we don't have.

Interviewer: Tell me the perception of patient outcomes; do you generally think the patients get the care they need or not.

Respondent: They don't get the care they need.

Interviewer: Why?

Respondent: Because as I told you, the number of health workers, for example if I operate on a patient I need to monitor him every fifteen minutes. So if I don't, the patient doesn't get the care he deserves to get and for sure no one will observe that patient because we are very few. So the patient is at risk; anything can happen when you don't know. Because, imagine coming here and sit for four hours when you have a pneumonia killing you or a heart failure where you can't breathe! So even if you treat such a patient, he can't say you have given him the care he deserves. Because, by the time someone leaves their home and comes, he has a problem.

Interviewer: Which means the waiting time for the patients becomes longer!

Respondent: Yes, the waiting time is a problem and even the interacting time with health personnel becomes very short because of the numbers. As I told you, if you have 180 patients, it is very difficult to sit and listen to that patient properly because as a minimum rule, you are supposed to clerk that patient for 45 minutes, but if you are one and given 180 patients a day, you will see 15 patients. So by the time you see 100 patients, you have given each patient like 3 minutes. So have you examined the patients? No! Because, I may come when I don't know that I have a heart failure, so it's you to listen to me and tell me. Despite you treating the fever, it doesn't mean I have received care. Two, investigations; as I told you, sometimes you want to do common investigations but the patient goes to the laboratory and find that it's not there, like for

an ECG, he has to travel this side just to do it. So I don't think the patient will get the care they wanted.

Interviewer: So tell me about patients' safety; are the patients safe with the quality of care you give them?

Respondent: Like in terms of?

Interviewer: Like a patient comes to you with a different diagnosis or symptom for example difficulty in breathing and fevers. When they come to you, are they safe in your hands that they will get the care they need?

Respondent: I think they are because we have qualified staff. The only thing that can change that is the numbers that may not provide services on time. Then absence of medicine because I might diagnose someone with heart failure and difficulty in breathing but I don't have furosemide to give. That would be the challenge but in terms of safety, when the health workers have the resources to use I think there's no problem there.

Interviewer: Have you had any preventable death at the hospital?

Respondent: Preventable death from rheumatic or?

Interviewer: Rheumatic Heart Disease and generally.

Respondent: So many times.

Interviewer: Why?

Respondent: You have said preventable or?

Interviewer: Preventable, like patient comes and you as a health worker you think this death would have been prevented.

Respondent: I hadn't understood the question. I have not. We have not had that one.

Interviewer: You have not had any preventable death? Like dying according to things that as a health worker you would have been able to treat?

Respondent: There's one kid who died because of lack of oxygen that time. We wanted oxygen but we didn't have oxygen, so we had to refer although it was referral without oxygen. We would have put the baby on oxygen and then we refer but we didn't have oxygen.

Interviewer: Then you lost the baby!

Respondent: We lost the baby, even getting an ambulance is a problem because we don't have a working ambulance.

Interviewer: Do you think patients are dying in the community without presenting to the hospital?

Respondent: I think so.

Interviewer: Why?

Respondent: I think for me it comes in two things; as I told you, the attitude they have about us. Sometimes they think that even if I go to that place, those people are very rude; you reach there when you are dying but someone says, "Who has sent you there?" If I go to the hospital, there's no medicine; they just tell me to buy and yet I don't have money, so why can't I just die from here? And three, it is the misinformation from local herbalists because they sometimes misinform the public a lot from the TVs. They teach them a lot of things like to just smear this or that once and it disappears, or that one can cure diabetes and hypertension and that by just swallowing two things, your diabetes is gone. So even the patient will remain there taking those herbs.

Interviewer: So as a health worker what in your opinion are the one or two things the ministry of health could do to improve patient outcomes?

Respondent: One, I think is to improve the health worker attitude towards patients although I don't know how they would do that. I don't know if they have to get someone to . . . I don't know, but health workers need to improve their attitude towards patients. And two, it is increasing the number of health workers and what they have to use in health facilities.

Interviewer: Okay. Anything else?

Respondent: Maybe also equipping health workers with listening skills, or maybe updating them because someone might have qualified ten years back and has never attended any CMEs and yet things have changed. For him, he is telling you those old things from ten years back! I think to also educate the patients to tell the community which services are available in nearby facilities because sometimes patients don't know which services are available; they first go to private clinics and from there they are given treatment for malaria for every condition, and that's when they come to the health facility when they're badly off and after wasting all the money.

Interviewer: What about the training in Rheumatic Heart Disease?

Respondent: That's the part that people don't know. General training is needed because that's where most health workers don't know.

Interviewer: Okay, thank you so much.